**FINAL PERFORMANCE REPORT**

**COVER SHEET**

**Grant #: 90AZ2774**

**Project Title: Rural Alzheimer’s Demonstration Project**

**Grantee Name/Address Iowa Department of Elder Affairs**

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**Iowa’s Rural Alzheimer’s Demonstration Project - AoA Grant # 90AZ2774**

# Final Grant Report for the period

# July1, 2004 to June 31, 2007

**“Enhancing capacity for dementia specific Adult Day Care and Respite for rural and emerging minority populations”**

**Participating Agencies:**

**Iowa Department of Elder Affairs**

**University of Iowa College of Nursing;**

**Subcontracting partners; Heritage AAA, Elder Services, Inc., Aging Services, Inc., Siouxland AAA, Big Sioux Chapter of the Alzheimer’s Association, Area XIV AAA & the Greater Iowa Chapter Alzheimer’s Association**

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Executive Summary

The Iowa Department of Elder Affairs, in collaboration with the Iowa Department of Elder Affairs (IDEA) and the University of Iowa College of Nursing (UI CON), has been engaged in developing and evaluating community based services for persons with dementia in the state of Iowa over the past 7 years under two grants form the Administration on Aging. These grant activities involved the cooperative efforts of the following contracted agencies, selected through a “Request for Proposal” procedure; the Heritage Area Agency on Aging through Elder Services, Inc. and Aging Services, Inc., two of the case management companies; the Siouxland Area Agency on Aging through the Big Sioux Chapter of the Alzheimer’s Association; and the Area XIV Area Agency on Aging in collaboration with the Greater Iowa Chapter Alzheimer’s Association.

In the current grant period, the involved agencies have completed a collaborative effort aimed to increase the capacity of Adult Day Health and Respite (ADR) providers in serving persons with dementia. Adult day services and respite care were identified by participants in the initial grant through various processes and service providers as important components of caring for persons with dementia and that there was a gap of these services in the state. Therefore, adult day and respite services were chosen as a target for the second AoA grant. The focus, in particular, was to enhance capacity to care for persons with later stages of the disease and those in rural settings as well as to begin to develop services that are more responsive to emerging minority populations. The process of the grant provided the state with a rich amount of information about the status of Iowa’s Adult Day Service providers in general and in regard to provision of dementia specific services, as well as valuable insights into the capability of rural communities to serve persons with dementia and their caregivers at home.

**Background & Significance**

Iowa is an aging state. According to 2000 census figures, 14.9% or about 437,577 people in Iowa are over age 65 (U.S. Census Bureau, 2004). Iowa ranks second by percent of people over age 85, third in the percentage of over 75’s, and fourth in those over age 65 (http://www.state.ia.us/elderaffairs/Documents/IowaFacts.pdf, 2001). About half of these elders live alone and about 10% care for someone else. There are 146,139 households headed by Iowans age 75 and over, with a median income of $21,230 ([www.seta.iastate.edu/census/vitalstats](http://www.seta.iastate.edu/census/vitalstats), 2004). At least 1/3 of these households have incomes of less than $10,000, thus eliminating the option of paying for in-home services, (http://www.state.ia.us/elderaffairs/Documents/IowaFacts.pdf, 2001).

Burden on family caregivers, not only to provide care independently but also to pay privately for services they can’t provide, is huge and expanding. Accessibility, availability and quality are all issues in community based services. These issues are compounded in rural and remote regions throughout the U.S. Underlying these issues for the increasing segment of the population are problems inherent for persons with dementia and their families. Estimates are as high as 50-60% of the population age 85 and older will have some form of dementing illness. Dementia is associated with high prevalence for NH placement, with many NHs reporting as many as 80% of their residents having Alzheimer’s Disease and Related Dementias (ADRD).

The National Adult Day Services Association reports one fourth of the US population provides care to a relative or friend 50 years of age or older. Fifty percent [50%] of ADR clients are cognitively impaired, 59% require assistance with two or more activities of daily living, and 41% require assistance with three or more ADLs. In addition at least 1/3 of these clients require weekly nursing service (<http://www.nadsa.org/press_room/facts_stats.htm>).

Alzheimer’s disease is the 7th leading cause of death in Iowa, about 26,000 deaths in 2000, (http://www.idph.state.ia.us/common/pdf/health\_statistics/vital\_stats\_2002\_brief.pdf, 2004). About 67,000 Iowans have Alzheimer’s disease or related disorders (Alzheimer’s Association, 1997). Ten to thirty percent [10%-30%] of those diagnosed with cognitive impairment live alone. Due to Iowa’s low population density, few rural services are available. While case management is available in all 99 of Iowa’s counties, care providers must cover great distances to serve relatively few seniors. The small service delivery system must serve all elders, regardless of diagnoses and was developed to help those who were cognitively intact. Services that are helpful to people with Alzheimer’s disease such as respite, adult day health programs and in-home health have limited availability and lack the economies of scale in rural areas. The job of caring for and working with persons with dementia and their families is complex and requires specific knowledge and skill development. Creating the most conducive environment both physically and in the human approach, as well as centering the care around the individual (person centered care) are critical in optimizing quality care and outcomes, and minimizing unwanted behaviors commonly associated with the dementia process. Currently there are only minimal standards of educational requirements set for health care providers in dementia competency. (Buckwalter & Maas, 2006).

Few service providers have the expertise needed to adequately serve clients with all but the earliest stages of dementia. Few persons with Alzheimer’s disease have needs judged to be reimbursed as “skilled care” by Medicare. Rural families affected by dementia lack access to nurses who can advise them on basic care management issues: personal care to a resistive loved one, behavior management, and medication. The result: premature nursing home placement. Iowa has one of the highest rates of nursing home placement in the nation.

Inherent in the second AoA grant is the underlying conviction that ADS & R services for persons with dementia and their families is a valuable service; one that assists in maintaining people in their homes safely, diminishing premature institutionalization, and promoting caregiver wellbeing. It has also been established that there are too few ADS & R services that are dementia capable, serve clients with higher levels of dementia, are accessible and readily available, and that the public has knowledge and utilizes the existing services to any great extent.

In the past, Iowa, like many rural states, has had relatively few a minority or culturally diverse groups in its population. Most Iowans (93%) are white, yet in recent years the population has begun to diversity. In 1980 and 1990 the population of people of African-American descent remained stable at 1%. In 2000, this increased to 2% and is expected to continue to grow. Perhaps the most change has been seen in the development of Latino populations. In 1980, Hispanic population was 0%; in 1990, 1%; and in 2000, 2%; (www.seta.iastate.edu/census/vitalstats, 2004). Often minority populations choose not to participate in census counts, resulting in a misrepresentation of true ethnic percentages. Between 1999 and 2030 the elderly minority population is expected to increase by 218% [US Department of Health and Human Services] The Caucasian elderly population is anticipated to increase only 81%. (<http://www.nadsa.org/press_room/facts_stats.htm>).

**Major Accomplishments & Activities**

This report, while focusing on the accomplishments of the second grant period from 7/01/04 through 6/30/07, will also incorporate knowledge gained through the entire seven year grant period as these two grants were integrally related. The grants garnered valuable information about available community based services for persons with dementia in the state of Iowa through testing out several models of nurse managed dementia care, varying models of respite care, surveying agencies and service providers in regard to how they provide services for persons with dementia, and providing training to case management, community college instructors, adult day service providers and other related services providers including assisted living and nursing home facilities. In addition, a number of capacity building conferences have been offered statewide on different aspects of providing care for persons with dementia.

**Adult Day Services in Iowa** **–**

***The******ADS Survey***

One of the first actions of the AoA grant was to survey all existing ADS and identified respite providers (per Iowa Department of Inspections & Appeals, [IDIA]) list and case management coordinators) in terms of their capacity for dementia clients and their education and training related to caring for persons with dementia, along with their concerns about the new rules and regulations and how they might apply to their agency. (See ADS Survey Results Report, 2005).

In Iowa the environment of Adult Day Service providers is changing due to modifications in the Iowa Administrative Rules and Regulations and how the Iowa Department of Inspections and Appeals is currently enforcing those rules. At the beginning of this grant, the numbers of ADS & R providers licensed in the state diminished from 83 providers listed to 34 providers with a capacity of 534 (as of January 2005). Currently there are 38 ADS with a capacity of 946. (July 2007). While the number of ADS decreased, reasons for this differ; the definition of ADS versus “day habilitation” constituted some of the decline, while some centers just closed for other reasons (lack of enrollment, fiscal viability). Many would argue that there already existed a gap in this type of service available especially for those in rural areas even prior to the decreased number of agencies.

In working closely with the Iowa Adult Day Services Association and several individual ADS providers, it is apparent that these agencies are struggling for survival; in terms of viability from a fiscal standpoint, because of the changing environment of healthcare and society, in addition to the lack of knowledge of their services and lack of connection of informal caregivers to self identify themselves as candidates for their services. Consumers are not savvy to what benefits come from the use of ADS & R services. Often heard from clients and their families is “I didn’t know about this type of thing”, or “I didn’t think my “spouse” would fit in or like this “babysitting service”. There is a misperception and a stigma in attending ADS. ADS & R services are one way demonstrated to reduce the caregiver burden and stress of caring for people with dementia (PWD) at home. Though sometimes due to staffing issues, ADS & R services are not always able to manage PWD in later stages of the disease process.

During the Annual 2006 Spring Conference of the Iowa Adult Day Service Association (IADSA), the program addressed sustaining business in ADS presented by two nationally known experts on the subject. (Jeb Johnson & Nancy Cox). Members were asked to rate their agency on “critical risk indicators” for remaining in business. Very few (10/48) could report that they were at low risk of closing, in fact most, according to the presented indicators, were in the “Danger Zone”- at high risk of closing. This is a dire predictor of the situation for Iowa’s ADS if it holds true. Part of the discussion focused on the barriers faced in sustaining their centers. The following are the challenges members identified in no particular order, though many were reiterated; transportation (cost, assisted vs. unassisted, service quality, & quantity); growth of clients, staff, space; staff orientation and training; funding/resources; fundraising especially as private paying clients are decreasing; marketing- how to inform the public, time and knowledge; corporate partnering or grant writing- lack time and know how; population integration- how to blend client diversity (of diagnosis and culture); diverse ability of staff; rural issues; stigma of diagnosis (both MRDD & Dementia, ADS for “kids”); changing environment, funding streams, system changes- keeping up; how to build relationships with potential clients before the crisis and need arises; meeting state rules & regulations; political environment- changing; how to manage client satisfaction; staff competence and moral; and space, environmental design especially in sub-par conditions.

Factors not listed in this discussion, but brought out in the day, and collaborated by the current president of that organization (personal communication with Marcie Cain, 8/2007), were about at the background and preparation of ADS directors. Often the people directing ADS are not trained or educated in business management, accounting, marketing, or education. These are people who may “come up through the ranks”, are social workers, nurses, may or may not have college degrees, and are often doing multiple roles within the organization. There is no formal education for or specifications for job skills to become ADS directors. Often directors are hired and given no orientation, may or may not have had experience in working in ADS, don’t know the rules and regulations, are learning everything and trying to manage everything and everyone without support. Sometimes there is an active and formal board which provides direction and consultation, sometimes not. Often mentioned was the fact that the administrator also had to act as a care provider since centers were so small, thus distracting them from activities that would promote expansion and solvency. Though these could be considered barriers, also demonstrated through attendance at this conference and membership in the organization, there appears high motivation to improve the situation. Center directors are very interested in growing their centers and improving the quality and breadth of their services. The content of this conference focused on models that worked, specific suggestions to promote growth and sustain business like marketing strategies. Participants were very engaged and interested in expanding this type of educational presentation.

**Impressions/ recommendations for ADS & R**

The following were evidenced through the grant activities, the formal Survey of ADS done in 2004, both formal and informal communication with case managers and service providers, as well as review of the State Unmet Needs survey, Iowa Caregivers Survey as well as other publicly funded and available reports.

* There are too few ADS through out the state and the number has declined
* Few existing ADS are truly dementia specific
* Staff training in dementia management, though basic educational requirements are mandated, is inadequate; many report they lack the ability to deal with difficult behaviors and express a need for more education in this area
* Even though staff maybe able to recite knowledge of dementia, their integration into practice is not supported (through video taped and observed behavior)
* Reimbursement for clients with dementia in ADS is under that of clients with mental retardation & developmental disabilities (MRDD), therefore acts as a negative incentive for agencies to serve clients with dementia
* Respite services are under valued and under reimbursed, especially in rural areas; costs for mileage and travel time are generally not covered and travel distances/time often significantly and negatively impact viability of providing the service
* There is little preparation in dementia care for respite workers available or utilized; leadership, financial management and personnel management skills are limited
* Nurses trained in dementia care can provide consultation and support to ADS & R that assists these providers in their care of persons with more advanced dementia
* Nurses can also help families see the advantages of ADS & R. They can offer unique contributions as support group facilitators
* ADS directors lack training and preparation for their roles, often they are in the position because they’ve been there the longest. Support needs to be available to encourage their business proficiency.

**Evaluation of the grant initiatives**

**Enhancing capacity for ADS & R**

Though enhancing capacity in ADS was the overall objective of the grant, each project approached it in different ways. The Big Sioux Area, mainly directed by the Big Sioux Chapter of the Alzheimer’s Association, focused on developing minority outreach. They produced and distributed physician kits that had been translated in to Spanish, as well as offering the ADS staff Spanish language classes. They integrated cultural activities and foods into their ADS and convened minority shareholders in developing awareness and outreach programs. Area XIV in collaboration with the Greater Iowa Chapter of the Alzheimer’s Association, initiated a drop in respite program in the community that previously had none. They are sustaining that program and looking for another site. The Greater Iowa Chapter has increased their involvement and community outreach into that region of the state. Data collection in these projects was significantly smaller, sporadic and they faced many unavoidable barriers (i.e. leadership and staff turnover). Therefore evaluation of these projects is limited. The Heritage Area Agency has had the largest project that involves the main evaluation component lead by the UI CON. They have continued the MLNS program, adding another MLNS to covered additional counties. They have also developed inroads into serving the Hispanic community through respite services. In addition, MLNSs have provided the training intervention for the ADS in the region. It is this last component that the report will focus discussions.

Outcomes evaluation in part were measured through data collected by the MLNS and ADS providers. Monthly MLNS reports for the 3 years of the grant were tabulated using descriptive statistics and included things like the number of dementia clients enrolled in case management not previously using that service, the level on the Global Deterioration Scale of clients being enrolled both in case management (MLNS cases) and those they enrolled in ADS, the average GDS level, numbers using ADS & R and who referred them.

Another method used to evaluate capacity change involved the research methodology of an intervention of education (provided in 3 sessions by the evaluators and/or the MLNS) with one group compared to a control group that did not receive education on dementia. Here we used an evaluation of the training itself, and a repeated measures evaluation of outcomes based on staff surveys of attitudes, perceived comfort, competence and job satisfaction, and family survey of change and satisfaction, and staff turnover rates (which have been linked to job satisfaction and sense of competence), and an agency profile before and after the intervention. Other data collected from the ADS providers included the number of persons with dementia, the GDS level and whether they saw any change over time in GDS level and numbers using ADS & R, as well as number of dementia specific ADS, number of dementia clients specific ADS can accommodate and serve. Another evaluation method used was based on research methodology by multiple researchers, (Gallagher-Thompsen et al, 1997; Skovdahl et al, 2004; Smallwood et al, 2001). For our purposes we designed a rating tool for taped & observed interactions. This instrument examined: demeanor of staff; positive affect, negative affect, mood & behaviors; level of engagement; and activity of staff. (See Appendix).

**Memory Loss Nurse Specialist Position**

***Demographic information from mlns reports***

NOTES: Figures below reflect those served by the MLNS in 5 counties in the Heritage region. Client totals do not include families served through the Alzheimer’s resource line number, educational offerings, MLNS outreach, support groups, or other direct client contacts where consultation, education and services are offered. Not all client records were included for statistical analysis as there were some records with missing data.

**Table 1. Total clients served by MLNS by county of residence**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **2004-2005** | **2005-2006** | **2006-2007** | **Total** | **Live Alone** | **Crisis** |
| **Benton** | 10 | 10 | 5 | **25** | **7** | **7** |
| **Cedar** | 12 | 9 | 10 | **31** | **6** | **6** |
| **Iowa** | 15 | 20 | 13 | **48** | **8** | **6** |
| **Johnson** | 41 | 43 | 34 | **118** | **15** | **20** |
| **Jones** | 7 | 20 | 7 | **34** | **7** | **0** |
| **Linn** | 63 | 44 | 26 | **133** | **35** | **10** |
| **Washington** | 16 | 17 | 11 | **44** | **3** | **3** |
| **Total** | **164** | **163** | **106** | **433** | **81 (19%)** | **52 (12%)** |

This table reflects the actual persons with dementia served, not the family members as they are not eligible for CM services unless they qualify independently. Over the three years of the grant, 52 calls were made by the family or client while they were in a situation described as a crisis, and 81 (19%) were found to be living alone. Both the number of clients considered in crisis and the number of persons living alone with dementia are less than in the previous grant. Both are highest in the larger cities than in the more rural counties.

**Table 2. Client enrollment by year enrolled and attrition**



A total of 116 (27%) persons exited the study over the 3 years of the grant. The highest percentage of clients exited because of moving out of their home to either a NH (34%) or into an AL (9%); 14% died, 10% moved away; and 15% the reason for exit is unknown. Other reasons for exiting were listed as hospice care, behavior change, family decision (each either 1 or 2%).

**Table 3. Number of Clients with GDS level at baseline (enrollment)/ total number enrolled**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **2004-2005** | **2005-2006** | **2006-2007** | **Total** |
| **Benton** | 3/ 10 | 10/10 | 5/ 5 | **18/ 25** |
| **Cedar** | 11/ 12 | 9/ 9 | 9/ 10 | **29/ 31** |
| **Iowa** | 11/ 15 | 15/ 20 | 11/ 13 | **37/ 48** |
| **Johnson** | 24/ 41 | 27/ 43 | 19/ 34 | **70/ 118** |
| **Jones** | 0/ 7 | 9/ 20 | 7/ 34 | **16/ 34** |
| **Linn** | 28/ 63 | 37/ 44 | 26/ 26 | **91/ 133** |
| **Washington** | 8/ 16 | 12/ 17 | 6/ 11 | **26/ 35** |
| **Total** | **85/ 164** | **119/ 163** | **83/ 106** | **287/ 433** |
|  |  |  |  |  |

These averages are based on available data, some clients were clients enrolled in the initial grant and did not have a GDS level, or were already enrolled in CM and transitioned to the MLNS, so did not have a baseline GDS. There was increased consistency in obtaining GDS scores which is a positive outcome of the training and consultation of the MLNS with the ADS.

**Table 4. Average GDS by county**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **2004-2005** | **2005-2006** | **2006-2007** | **Total** |
| **Benton** | 5 | 3.9 | 3.4 | **3.9** |
| **Cedar** | 5.2 | 5 | 4.3 | **4.8** |
| **Iowa** | 4.3 | 4.5 | 4.3 | **4.4** |
| **Johnson** | 4.5 | 4.9 | 4.7 | **4.7** |
| **Jones** |  | 3.9 | 3.6 | **3.8** |
| **Linn** | 4.5 | 4.2 | 3.6 | **4.1** |
| **Washington** | 4.1 | 4 | 5.2 | **4.3** |
| **Total** | **4.6** | **4.3** | **4.2** | **4.3** |

Some client’s GDS scores were indicated as (3 or 4). In this case an average score (3.5) was used for those clients. One explanation for the apparent decrease in GDS score in all but Washington county maybe that these counties have participated in the grant for years and experience has demonstrated the higher level impairment (higher GDS score) reach out for help, therefore those with more impairment may have been enrolled earlier in the first grant. Washington County is a new grant county and therefore GDS scores were more in line with the higher scores seen in the first grant; as more people recognized the MLNS, more people called with more problems.

**Table 5. Global Deterioration Scale of all clients**



The chart above represents all the GDS scores by category with 2 being the lowest (mild impairment) and 6 being later stage (severely impairment). As indicated by the chart, the majority of clients fall in the middle categories, 4 & 5 (69%), or in a period of the disease characterized by significant symptoms affecting quality of life and abilities. The GDS average score declined in later grant years which could be an indication of several factors: that the MLNS position was becoming recognized and people are seeking assistance earlier in the disease process that the symptoms of dementia are being recognized earlier or that providers in the area are aware of a new resource for their clients and referring. There is evidence to support that all 3 of these factors may be involved.

There was a wide discrepancy in MLNS productivity. This maybe have been due to many factors, including a different set of expectations and definition of the role by the agencies that hired the MLNS, in addition, one MLNS was more experienced & knowledgeable in dementia care having served the grant for 6 years. Travel distance to rural communities, comfort and established relationship with agencies from previous years, reputation and requests for her at trainings, administrative support of autonomy, and position understanding, among others maybe contributing factors to this discrepancy. Both MLNS provided extensive community and agency educational offerings, initiated and facilitated support groups, provided monthly consultations to ADS and one developed and implemented a training for respite providers.

***Evaluation of ADS educational intervention***

A variety of methods were used to evaluate the staff educational sessions in a repeated measures format. Data was collected at baseline, 6 and 12 month periods following the training. In addition, video taping and observational sessions in each of the intervention sites were completed for those individuals who consented. This was done by trained research assistants. The evaluation tools included a modified Knowledge of dementia test, & a staff survey which was comprised of a satisfaction component, a client observed behaviors frequency and behavior irritation scale. An evaluation of each individual educational session was also completed. In addition, families were surveyed for satisfaction with the ADS.

**Table 6. Overall staff evaluation of dementia training sessions**

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **Overall** |
| Training 1 | 1.44 | 1.37 | 1.89 | 2.69 | 1.41 | 1.59 | 1.67 | 1.48 | 1.69 |
|  | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** |  |
| Training 2 | 1.43 | 1.5 | 1.8 | 2.79 | 1.8 | 1.47 | 1.47 | 1.9 | 1.76 |
|  | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** |  |
| Training 3 | 1.36 | 1.4 | 1.92 | 2.92 | 1.36 | 1.48 | 1.48 | 1.44 | 1.66 |

(1= excellent or highest rating, 2= very good, 3= ok or average, 4= not so good, 5= poor, lowest rating)

The questions on each evaluation were consistent:

1. The material presented was applicable and useful in the ADS environment.

2. I will use the concepts presented in my work at the ADS.

3. There was new material presented.

4. There was too much material presented.

5. The level of material presented was understandable for me.

6. The material presented met with my expectations.

7. The information included in this training was detailed enough.

8. The material in this module was presented in a way that I could learn.

The trainings provided met with enthusiasm and interest, and as the table indicates received very high ratings for all 8 questions. Feedback from staff and administration was very positive. The interactive sessions are attended by all staff, and MLNS utilized real situations to integrate change behavior into the ADS settings. They actively work with the staff on individual “problem” behaviors in each center to demonstrate how the taught strategies are effective. An anecdotal response from staff and ADS administration was very positive. The education provided during the training was reinforced by the MLNS s in the ADS settings. MLNS were available for consultation and working with the staff during client times. This was intended to enhance the integration of behaviors and skills learned in the training.

**Table 7. Response rates and number of staff & family surveys**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Baseline** |  | **6 month** |  | **12 month** |  |
| **Intervention Sites** | **Staff received/ sent** | **Families received/ sent** | **6 mo. Staff received/ sent** | **Families received/ sent** | **12 mo. Staff received/ sent** | **Families received/ sent** |
|  | 33/ 44 | 134/ 273 | 22/ 27 | 79/ 138 | 15/ 23 | 53/ 79 |
| **Response rates** | 75% | 49% | 81% | 57% | 65% | 67% |
|  |  |  |  |  |  |  |
| **Control Sites** |  |  |  |  |  |  |
|  |  |  |  |  |  |  |
| **Response rates** | 24/ 27 | 39/ 136 | 19/ 24 | 23/ 37 | 22/ 23 | 13/ 23 |
|  | 89% | 29% | 79% | 62% | 96% | 57% |

Response rates were based on the number sent out per data collection point so even though the real numbers of participants decreased the percentages were variable based on the returned responses. The response rates were all in an acceptable range except for the initial family response rates. Some of this is due to the one control agency, despite repeated requests, did not send out the family surveys (per IRB, the agency was to send out the initial family surveys to protect privacy & confidentiality).

**Table 8. Caregiver Satisfaction**

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  |  | **1 Average (satisfaction)** | | | |  |  | **2 Average** |  |  |  |  |
| **Intervention** | **n** | **baseline** | **n** | **6 mo** | **n** | **12 mo** | **n** | **baseline** | **n** | **6 mo** | **n** | **12 mo** |
| **Agency 1** | 46 | 4.08 | 33 | 4.29 | 17 | 4.16 | 42 | 3.13 | 33 | 3.41 | 19 | 3.47 |
| **Agency 2** | 33 | 4.17 | 16 | 4.12 | 14 | 4.33 | 33 | 3.3 | 14 | 3.37 | 14 | 3.26 |
| **Agency 3** | 28 | 4.31 | 18 | 4.35 | 11 | 4.4 | 27 | 3.44 | 17 | 3.15 | 11 | 3.86 |
| **Agency 4** | 8 | 4.42 | 4 | 3.27 | 3 | 4.38 | 8 | 2.59 | 4 | 3.17 | 3 | 2.6 |
| **Agency 5** | 14 | 4.23 | 8 | 4.41 | 7 | 4.28 | 14 | 3.04 | 7 | 3.74 | 7 | 3.06 |
| **Total** | **129** | **4.19** | **79** | **4.23** | **52** | **4.28** | **124** | **3.17** | **75** | **3.51** | **51** | **3.43** |
| **Control** |  |  |  |  |  |  |  |  |  |  |  |  |
| **Control 1** | **11** | 4.27 | **5** | 3.56 | **3** | 3.98 | 11 | 3.1 | 4 | 1.97 | 3 | 3.02 |
| **Control 2** | **3** | 4.57 |  |  |  |  | 3 | 4 |  |  |  |  |
| **Control 3** | **24** | 4.34 | **18** | 4.14 | **9** | 4.38 | 20 | 3.51 | 18 | 3.59 | 9 | 3.51 |
|  |  |  |  |  |  |  |  |  |  |  |  |  |
| **Total** | **38** | **4.34** | **23** | **4.01** | **12** | **4.27** | **34** | **3.39** | **22** | **3.28** | **12** | **3.38** |

There were two forms of satisfaction surveys used. The second survey asked for areas of dissatisfaction to try to control for often inflated ratings often obtained with satisfaction surveys. However, the satisfaction level was quit high for both surveys. There was little difference between the intervention and control levels of satisfaction.

**Table 9. Staff assessment of most frequent & upsetting behaviors**

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **The most frequently occurred behavior** | | |  |  |  |  |  |
| **Intervention** | baseline | Asking the same question over and over again | | | | (3.25) |  |
|  | 6 month | Asking the same question over and over again | | | | (3.68) |  |
|  | 12 month | Asking the same question over and over again | | | | (3.40) |  |
| **Control** | baseline | Asking the same question over and over again | | | | (2.48) |  |
|  | 6 month | Forgetting what day it is (2.74) | | |  |  |  |
|  | 12 month | Being constantly restless (2.76) | | |  |  |  |
| **The most upsetting trigger** | |  |  |  |  |  |  |
| **Intervention** | baseline | Engaging in behavior that is potentially dangerous to self or others (2.28) | | | | | |
|  | 6 month | Engaging in behavior that is potentially dangerous to self or others (2.09) | | | | | |
|  | 12 month | Engaging in behavior that is potentially dangerous to self or others(2.93) | | | | | |
| **Control** | baseline | Engaging in behavior that is potentially dangerous to self or others(2.82) | | | | | |
|  | 6 month | Engaging in behavior that is potentially dangerous to self or others(2.67) | | | | | |
|  | 12 month | Engaging in behavior that is potentially dangerous to self or others(2.38) | | | | | |

There is consistency in what was identified as both the most frequently and most upsetting behaviors in the intervention and control sites. This has implications for training and interventions. While these behaviors were identified by the surveys they were not identified during the training sessions.

**Table 10. mKAT knowledge of dementia test scores**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Baseline** | **%** | **6 month** | **%** | **12 month** | % |
| **Intervention** | N= | Mean | N= | Mean | N= | Mean |
|  |  |  |  |  |  |  |
| **Total** | 29 | **77** | 14 | **73** | 15 | **77** |
| **Control** |  |  |  |  |  |  |
| **Total** | 24 | **73** | 19 | **73** | 22 | **76** |
| **Range** |  | 26-98 |  | 48-96 |  | 22-98 |

The scores indicate there are many people who scored very well on the test as indicated by the mean scores. There was quite a range indicating that there are a few who did not score well, perhaps because they are new. The scores from data point to point are not significantly different. This needs to be viewed in relation to the staff turn over variables to get a clearer picture of knowledge. The N decreased in both intervention and control group, with the control group having a better response rate. It is not discernable from the data collected whether this is due to turn over or just who chose to return the survey and who did not.

**Table 11. Agency Staff Turn Over & “Stay” Rates**

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Total staff during eval. Period** | **Termination during eval. Period** | **Remaining staff at end of eval. Period** | **Remaining staff 6 month tenure** | **Remaining staff 1 year tenure** | **Remaining staff 2 years tenure** | **Remaining staff > 2 years tenure** | **Stay Rate at end of eval. period** | **Turn Over Rate during eval. period** |
| **Intervention** |  |  |  |  |  |  |  |  |  |
| **Agency 1** | 19 | 9 | 10 |  | 2 | 1 | 7 | 53% | 47% |
| **Agency 2** | 11 | 3 | 8 |  | 2 | 1 | 5 | 73% | 27% |
| **Agency 3** | 16 | 7 | 9 |  | 4 | 2 | 3 | 56% | 44% |
| **Agency 4** | 6 | 3 | 3 | 1 |  | 2 |  | 50% | 50% |
| **Agency 5** | 8 | 2 | 6 |  |  | 4 | 2 | 25% | 25% |
| **Total** | 60 | 24 | 36 | 1 | 8 | 10 | 17 | 60% | 40% |
| **Control** |  |  |  |  |  |  |  |  |  |
| **Control 1** | 6 | 1 | 5 |  |  |  | 5 | 83% | 17% |
| **Control 2** | 5 | 2 | 3 |  |  | 1 | 2 | 60% | 40% |
| **Control 3** | 12 |  | 12 |  |  | 3 | 9 | 100% | 0% |
| **Control 4** | 3 |  | 3 |  |  |  | 3 | 100% | 0% |
| **Total** | 26 | 3 | 23 | 0 | 0 | 4 | 19 | 84% | 16% |

This chart outlines both the number of staff who have remained in employment for a time and the termination rates. There is quite a range of rates, but some of this variance can be attributed to staff sizes. The most positive and significant is the stay rates for both the control and intervention sites had high stay rates, which really tell us more about the stability and continuity of the program than turn over rates. This was a descriptive study of stay and turn over rates in ADS which should be helpful information as other people evaluate ADS.

Analysis of evaluation data indicate in summary that: educational offerings must be more than didactic and need to include experiential activities; video taping as an educational tool is powerful for staff self assessment; agencies are interested and value educational opportunities, but lack resources both financially (staff time & program costs) and availability of quality offerings; & administrative support is essential for integrating change behavior into practice. While staff scored highly on baseline knowledge tests, there was a gap in putting that knowledge into practice; this was particularly evidenced through video taped and observational methodology.

**Table 12. Video taping evaluation**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Facility** | **# Observation** | **Positive Affect**  **Present Absent** | | **Negative Affect**  **Present** | **Moon** | **Behavior** |
| Agency 1 | 4 -10 min. | 38 x | 22 x | 1 instance  Not tracking | 1 neutral  All others happy | 2 no eye contact |
| Agency 2 | 7 -10 min. | 46 x | 19 x | None | 1 x neutral  All others happy | 2 instances  no eye contact ; 1 unclear expectations |
| Agency 3 | 1- 10 min. | 47 x | 37 x | 2 instances  Not tracking | 5 happy  4 neutral | 5 instances  Sour looks (2)  No eye contact (2)  Ignoring need for help (1) |
| Agency 4 | 7 -10 min. | 31 x | 55 x | 8 instances | Mostly neutral | 6 instances  Sour looks (2)  Withdrawal (1)  No eye contact (3) |
| Agency 5 | 8 -10 min. | 93 x | 27 x | 0 | Happy | 6 instances  No eye contact when talking with clients (3 x)  baby talk (1)  instance of multiple instructions (1)  Sour look (1) |

Inter-rater reliability was established by having 2 raters rate one 10 minute observation.  We had 90% agreement and then discussed the differences so they would be consistent on subsequent rating.

Preliminary findings from the video taped and observational data suggested there was some positive interaction there were opportunities for more that were not taken advantage of. Cueing was not seen often and there was often failure of engagement of more withdrawn clients. Overall the interactions are positive with most staff presenting a happy mood.  There are minimal instances of negative behavior, however if these continue over the course of the day they may have serious consequences.  Most instances involve no eye contact, withdrawal or ignoring or sour looks.  These are all actions that discourage interaction.  While there were many instances of positive affect there were also numbers of missed opportunity for positive affect.  It is difficult to compare facilities in this evaluation because of the uneven number of recordings.  The primary use for this evaluation will be feedback to facilities about the aggregate findings and the implication for training.

**Conferences sponsored**

***“The N.E.S.T. Approach; An Interdisciplinary Program for Adult Day Services”*** was presented on May 5, 2007 at Camp Sunnyside, Ankeny, Iowa. This was attended by 50 people, with 26 of 34 licensed ADS represented in this 2 day training. Disciplines including nurses, SW, activities coordinators, volunteers, directors, administrators, community college instructors, and direct care workers were in attendance. This conference presented an evidence-based practice guide for disturbing behaviors of dementia for the geriatric care worker. There was also a component of this conference that presented the “Voice of the person with dementia”, a presentation by Dr. Richard Taylor, author of *Alzheimer’s: From the Inside Out*, who is an international advocate for listening to the voices of people with the disease.

***“Aging, Diversity & Dementia: Increasing Capacity in the Aging Network in Iowa***”, was sponsored in 2005. The target audience was service providers in the Aging network across the state, and included multidisciplinary professionals from social work, nursing, case management as well as from a variety of settings. Speakers included experts on cultural competence, diversity and health disparities, translation & interpretation services, as well as the National Associate Director of Minority Outreach and Inclusion for the Alzheimer’s Association, who spoke on minorities and dementia. A speaker from the Iowa Department of Public Health spoke on the diversity of populations in Iowa and how to engage them, and a consumer who provided insights into her Hispanic family’s experiences in the service network system. There were approximately 50 people in attendance. Evaluations of the conference were very positive; the response rate for evaluations was 62%. The primary accomplishments of the conference was that it increased consciousness of the need to address minority issues and gave participants potential strategies and tools for doing that.

***Long term care conference sponsorship.*** The University of Iowa Adult & Gerontologic Area and the Hartford Center for Geriatric Nursing Excellence put on an annual long term care conference. The AoA grant supported these opportunities for enhancing community awareness and competence for providers.

***“Breaking the Code: Dimensions of Wellness”,*** was the title of the conference in 2006.

While the title did not include dementia, caring for the person with dementia was integrated throughout the presentations as these intervention strategies are important components of dementia management. Topics covered in the meetings were; an overview of the litigation process and the role of documentation minimizing liability with specific topics including falls, prevention, restraints, wandering, and elopement. There was also a focus on promoting wellness in older adults and healthcare providers. Sessions concentrated on the six dimensions of wellness: physical, social, emotional, intellectual, spiritual, and vocational.

***“The heart of Caring: Helping Elders Grow”.*** In 2005 the theme of the conference was “to recognize and encourage more positive and creative approaches relating to older people with Alzheimer’s and related disorders. The Leadership Workshop was designed to look at the challenges of caring for older adults with Alzheimer’s disease and related disorders. Creative interventions and strategies implementing techniques new to the field”, were the focus. As part of the conference there was a special event play, ***“A Quiet Moment”,*** was held. “A Quiet Moment”, was described as a funny, touching and poignant play about the effects Alzheimer’s disease has, not only on the individual, but on the individual’s family.

**Community College Outreach & Education**

The UI CON has an established collaborative effort with Community College network. The UI CON provided revisions to the nursing assistant training manual for the chapter on disease specific (dementia) care. Many of these were accepted by the committee, and the UI CON presented the information with teaching tips to the community college CNA trainers. This group of 15 community colleges provides most of the CNA training in Iowa. The UI CON was requested to do a similar review for the activities directors’ manual and incorporate the new CMS guidelines in those revisions. This work is in progress.

**Diversity inclusion & competnece for dementia specific services**

Each region approached the issue of diversity outreach differently. This was a large task that had varying support in terms of a focus. Many providers in Iowa still do not see a need for or have resources to outreach to minority groups in specific. They have a “one style fits all” approach. They feel their resources are limited and presently the minority populations are proportionately small.

**Table 13. Ethnic Participants (new)**

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  | **2004-2005** | **2005-2006** | **2006-2007** | **Total** |  | Code for Ethnicity | |
| **Benton** |  |  |  |  |  | 1. = Caucasian | |
| **Cedar** |  |  |  |  |  | 2. = African American | |
| **Iowa** |  | 1(2) |  | **1** |  | 3. =Hispanic/ Latino | |
| **Johnson** | 2 (2, 3) | 3 (2, 6) | 2 (3, 2) | **7** |  | 4. = Native American | |
| **Jones** |  |  |  |  |  | 5. = Asian | |
| **Linn** |  |  |  |  |  | 6. = Other (State) | |
| **Washington** | 1 (3) | 1 (3) | 2 (3) | **4** |  |  |  |
| **Total** | **3** | **5** | **4** | **12** |  |  |  |

Numbers in ( ) indicate the Ethnicity. Ethnicity was not indicated in all reports.

* In regard to diversity service provision; there is a lack of prepared service providers in terms of language and cultural competence, there is lack of interest or recognition of need by service providers who feel their baskets are too full already and the misperception that minority communities “take care of their own”. In contrast, this grant found that when competent, language specific services are provided, service providers are welcomed and utilized by minority populations.
* There is also a lack of awareness of the system, how it works and what is available by minority groups. Issues of immigration and legal status create reluctance to access services, even if they are knowledgeable about what is available.
* Service outreach to minority communities requires more than publishing information in the first language; marketing needs to be targeted at what is culturally appropriate, connection needs to be made with and through a trusted source within the community.
* There is a reluctance to use the Safe Return program within the Hispanic community because of fears with regard to immigration status & the Department of Immigration and Naturalization Service (this program requires that participants register their address). Formal statistics indicate that the Hispanic population in Iowa has grown to be the largest race or ethnic minority group *(State Data Center of Iowa and the Iowa Division of Latino Affairs, 2005)*.
* Safe Return & other ID bracelets are not bilingual; further endangering non-English speaking persons with dementia who may wander or become lost. This creates difficulties not only for the person with dementia (who may become even more agitated and frustrated) but with public officials like law enforcement officers who cannot communicate with or already lack knowledge of working with people with dementia. (Though this was discussed in year 1 of the grant, there was no action to this end).
* There are special needs of different sub-groups of people with dementia; those with early stage disease, those with early onset dementia (diagnosis under 60 years old), and those with dementia living alone. These have different and special considerations.

**Overall BARRIERS**

***Sustainability barriers/ strategies to overcome***

Sustainability is an ongoing barrier for agencies. Busy agencies with an orientation toward service compromise home and community based service provider’s abilities to seek out and go through the lengthy and technical process of grant writing. Though they acknowledge the importance of seeking external funding, it is often beyond their resources to develop their grant writing skills to be successful in this adventure. Social program dollars are limited and though Iowa is not seen as a poverty state, many of the rural areas are poor. In rural areas especially, there are not generally large local benefactors, philanthropic entities or corporations available to approach for needed funding.

Two of the project areas were not successful in developing the position of MLNS into their programming. One region has not been exposed to this position before (Area XIV), and has concentrated their efforts on developing the main goal of their project, a drop in respite center. After consultation and networking with the existing MLNS, they expressed the potential for and benefits of this type of position, and renewed efforts to find someone for this role. They were successful in identifying a qualified, interested person. However, due to conclusion of the grant, initiating this position is not feasible. The other area (Siouxland Area) has had trouble hiring and sustaining a person in this position, even though they have had a successful MLNS/ NCM in the previous grant. This partner agency (Big Sioux Chapter of the Alzheimer’s Association) has had tremendous turnover of staff, difficulty in staff retention and had a gap in leadership. Attention to another new position was not within their capacity or interest during the final year of the grant.

Efforts to address sustainability of the MLNS position in the Heritage AAA region include investigating the idea of co-contracting the services with other agencies. This strategy was used with one agency, Aging Services Inc., who collaborated with Mental Health agency to split the time and salary of the MLNS. This was an ideal fit as the MLNS handled the geriatric cases for the mental health agency and many of those clients had a diagnosis of dementia already. So her services were expanded through that collaboration. The UI CON continued to provide training and support for this position. At the request of the other agency, Elder Services, Inc. the UI CON co-authored two grants to continue the position of the other MLNS. The outcome of those awards will not be known prior to submission of the grant end report.

Writing grants is being encouraged and technical assistance was provided to support outreach dementia projects. An example is the Johnson & Johnson, Roselyn Carter Institute for Caregivers Program grant submitted by ESI & the UI CON for money to support expanded MLNS services and CG programs in 2007-2008. Other grant opportunities, initiated by the DEA, have been circulated to subcontracting agencies as appropriate. Offers by the UI CON have been made to assist in grant writing or review.

***Lack of qualified prepared professionals in gerontology***

One of the major components on implementation was the MLNS position. In 2 of the areas, efforts to find someone to fill this position were attempted. Neither had luck in attracting qualified and interested nurses. There are several factors related to this. This position is “soft” money- the job is not secure and this is not a typical role for a nurse. There is a shortage of nurses in rural Iowa and those around can find more “prestigious” and higher paying jobs in the hospitals/ clinics and nursing homes. Several of the agencies were not with the grant in the first cycle. In that grant we learned that this position needed to be a designated position, not an “add-on” responsibility role. When agencies committed to identify an exclusive position for a MLNS, they were much more successful in finding and maintaining this position. Despite the shared knowledge from the first grant, other agencies chose other recruitment and hiring strategies.

S***ystems change barriers/ strategies to overcome***

Changes in the case management system in Iowa continue to unfold. These modifications continue to prove a distraction for agency personnel, with effects on the grant beyond our control. The grant meetings and SWC meetings have benefited the participants in that this provides an opportunity for discussion, personnel feel they are more in touch with developments and have an opportunity to impact the outcomes by being included in more formal discussions where DEA & DIA representatives are present.

A statewide barrier found in the case management system is the absence of cognitive status sections in the assessment tool. The MMSE was taken out of a tool previously used and when Iowa starting using the OASIS, cognitive screening was totally eliminated. This creates the situation that often case managers over-look the only question that could indicate cognitive process alterations. The question is stated as a “Mental Health” issue, an ethical dilemma for many in that it can be seen as “regressing” the conceptualization of the disease to one that is not physically based. This “mental illness’ still carries a stigma and has economical consequences. This contributes to many clients who have dementia being under diagnosed, under treated, under referred, and under served. Grant staff continues to have dialogue with relevant positions about ways to be more comprehensive and descriptive in regard to dementia assessment and services. One success was in having topics related to dementia be included in the list of acceptable topics of Continuing Education conferences for CM personnel.

***Direct care barriers***

The ADS agencies in Iowa continue to struggle with many issues. Of primary concern is that of reimbursement rates for ADS. This impedes the financial solvency of ADS and is especially pertinent in rural areas that have the issues surrounding transportation. In rural areas transportation is an essential service for ADS, compounding their already restricted resources. Another barrier faced in providing direct service in rural areas is that the Iowa’s elderly waiver program is restricted to pay only respite hours for time actually spent at the client’s home, not travel time. This makes it extremely difficult to provide respite services to those in rural areas where a drive time could be over an hour each way, especially if the respite is only for a few hours.

Several agencies identified and that had indicated an interest in participating in the evaluation and training component of this grant, have since been closed. The reasons have generally had to with changes in the enforcement and their understanding of rules and regulations, low participation, and lack of administrative support *(associated with a hospital and the hospital no longer felt the ADS was viable)*. This will have the effect that the sample size in the evaluation component will be small. Most ADS in the area are small making the pool of potential participants limited.

Lack of Spanish speaking direct care workers, especially in the aging network, is a prevalent barrier in rural Iowa *(Older Americans Report, February 2005)*. In addition, there is a lack of knowledge and awareness of service options by the elderly Latino population group. Consequently this translates into minimal amount direct service utilization by the elderly Latino population. In establishing relationships and becoming more closely involved in minority communities, an issue in the Safe Return program has come up. There is a reluctance to use Safe Return since it requires that participants register their address fostering Department of Immigration and Naturalization Service fears. Formal statistics indicate that the Hispanic population in Iowa has grown to be the largest race or ethnic minority group *(State Data Center of Iowa and the Iowa Division of Latino Affairs, 2005)*. This highlights the need to address the growing needs for minority populations in Iowa.

Limited resources available for sustaining the efforts of the grant remain a barrier. Even though the agencies see the importance and benefits of having a MLNS, and the ADS are finding valuable resources in the grant, additional funds needed to expand the project through out the state have been difficult to find. Agency staff are not prepared to write grants, have little time to devote to developing these competencies, and are conceptually oriented to providing service not fund raising.

***Communication***

One solution used to address this issue were the attempts at having bi-monthly work group meetings with “mandatory” attendance. This only partially worked. One agency consistently didn’t send a representative and frequently there were no available options to gather the entire group as it was large and the regions were geographically spread out. This was a difficult balance as there is very little administrative money considering geography and schedules, making travel essential to attend. There were tangible outcomes when they did participate as participants expressed they learned a lot and gained insights as to how to implement more effectively. However, when faced with scheduling conflicts, this grant was a smaller source of funding and therefore was lower on the priority list.

Turnover of grant personnel both at the state level and in agency levels has been a barrier. We have had agency turn over of critical positions. Bringing these key partners up to a productive level has been difficult as the grant is a minor priority in their scope of work. The level of funding especially for administrative component is insufficient to motivate the level of action desired.

Support and collaboration between agency personnel was a critical component of successful completion of all components of the grant. This mutual collaboration was not always the case as with many agencies, resources are stretched and with geographical considerations, interagency support was not always optimal.

***Additional strategies to address barriers***

***Strategies used for enhancing capacity of ADS & R***

One barrier identified by ASD providers in both the ADS survey and at the IADSA annual conference was their difficulty in understanding, and then implementing new rules and regulations from the State. Several strategies were used in targeting this barrier. One was the formation of the Statewide Committee to review materials, offer a forum for discussion and bring together interested parties for dialogue. This committee included members of the state regulatory and enforcement agencies, and invitations for participation were sent to members from the LTC industry, the community college network, Iowa Caregivers Association, IADSA members, and the 4 Iowa Alzheimer Association offices. All ADS directors were sent a special letter of invitation. All participants felt this was a valuable use of time and served this purpose.

Another strategy was to work on media campaigns to help educate the public about adult day services and respite. The Heritage region chose to do this by featuring a series of articles focusing on different stories from and about benefits of ADS & R in their monthly newsletter. This idea was presented to other regional projects during work group meetings, and the articles were shared as examples. This marketing concept was promoted at the IADSA meeting. In the Heritage region it proved to be successful in garnering many phone calls both to the local ADS and to the MLNS for referrals.

**Overall outcomes and summary**

Considering all data collected, even though the educational intervention had mixed results, the entirety of the data indicate that capacity was enhanced in the intervention site ADS. These are strategies that could be used and replicated to increase capacity in this state and others. Outcomes observed or reported include;

* All interventions sites report increased numbers of clients with dementia served and all agencies but 2 reported their clients had more progressed stages of the disease
* 1 ADS has a new facility & added 8 spots for dementia specific clients with an AD “room”; they have hired the MLNS part time for education, support on client issues and assessments and behavior management and community educational outreach
* Minority awareness has been increased in 2 of the regional projects; both in written materials (the MD kits in the Big Sioux region) and in respite and service in the Heritage region; and through the conference in year 2
* There is 1 new drop in respite center (Area XIV) and 2 new mobile respite offerings in the Heritage region
* There is a disconnect between staff actual practice & self assessed ability
* Key to enhancing capacity for later stage dementia is staff education/ development of communication skills, but 6 hours of training is not adequate and training needs to include more than didactic presentations.

**Table 14. Agency profiles related to dementia Pre- and Post- survey**

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **a = pre- b= post** | **ADRD capacity** | **GDS1** | **GDS2** | **GDS3** | **GDS4** | **GDS5** | **GDS6** | **Change in ADRD Cap.** | **GDS 3,4,5,6** |
| Agency 1.a | 14 | 39 | 30 | 19 | 13 | 15 | 14 | 6 | 61 |
| Agency 1.b | 20 |  | 10 | 25 | 20 | 10 |  |  | 55 |
| Agency 2.a | 10 | 0 | 1 | 5 | 20 | 7 | 3 | 30 | 35 |
| Agency 2.b | 40 | 11 | 7 | 16 | 15 | 12 | 3 |  | 46 |
| Agency 3.a | 40 | 23 | 9 | 10 | 2 | 3 | 2 | 5 | 17 |
| Agency 3.b | 45 | 5 | 4 | 4 | 3 | 1 | 1 |  | 9 |
| Agency 4.a | 6 | 1 | 6 | 6 | 3 | 0 | 0 | ? | 9 |
| Agency 4.b | NR |  |  |  |  |  |  |  | NR |
| Agency 5.a | 5 |  |  |  |  |  |  | 35 | NA |
| Agency 5.b | 40 | 2 | 7 | 4 | 6 | 1 | 4 |  | 15 |
|  |  |  |  |  |  |  |  |  | 0 |
| Control 1.a | 4 | 5 | 1 |  | 1 | 1 |  | same | 2 |
| Control 1.b | 4 | 14 | 10 | 7 | 3 | 5 | 2 |  | 17 |
| Control 2.a | 4 | 1 | 5 | 1 | 2 | 1 | 1 | same | 5 |
| Control 2.b | 4 | 9 | 2 | 1 |  |  | 1 |  | 2 |
| Control 3.a | 10 | 2 | 23 | 30 | 16 | 15 | 4 | 38 \*new director | 65 |
| Control 3.b | 48 | 15 | 20 | 24 | 10 | 9 | 1 |  | 44 |
| Control 4.a | NR | 10 | 1 | 6 | 1 | 5 | 1 | ? | 13 |
| Control 4.b | NR |  |  |  |  |  |  |  | NR |

**Dissemination**

***Trainings, Presentations, & Posters***

***\*****This does not include all trainings and community education talks provided as these were a major focus of the grant and the MLNS and other grant partners provided in-services, community education presentations and smaller consultations on a regular basis. This was done not only with intervention sites, but other agencies; NHs, ALs, home health agencies, community groups, support groups as requested and as time allowed.*

Bossen, A., Yeggy, L., Gregor, K., “An introduction to the N.E.S.T. Approach to behavior and environmental management in dementia”. Staff training at Center for Active Seniors, Davenport, IA. June 13, 19, 27th, 2007.

Specht, J., Bossen, A., “Listening to the Voice of the person with dementia: Clinical implications”, presentation to the School of Nursing and others, University of Iceland, Reykjavik, IS. May 22, 2007.

Bossen, A., Lynch, N., McKay, S., “Restraint free care and Evidence based practices in managing disturbing behaviors of dementia” presented as part of Pressure Ulcers & Restraints: Improving Outcomes, Surveyor Training, Iowa Department of Inspections & Appeals, Des Moines, Ia. May 8, 2007.

Bossen, A.L. Update on the AoA Grant; Where we are and where we’re going”, and “An Introduction to N.E.S.T.”, Wesley Acres Methodist Homes, Des Moines, Iowa, May 4th, 2007.

Specht, J., Bossen, A., “One piece of the puzzle”, presented at the National Council on Aging/ American Association on Aging Annual Joint Conference, Chicago , Ill. March 7-10, 2007.

Specht, J., Bossen, A., “Enhancing Capacity in Adult Day Care for Persons with Dementia”, presented at presentation a the 59th Annual Scientific Meeting of the Gerontological Society on Aging, Dallas, TX, November 16-20, 2006.

Bossen, A., Hornbuckle, T., “Update on Progress of the Iowa ADDGS Project”, presentation to the Iowa Commission for Elder Affairs, Des Moines, Iowa. October 20, 2006.

Bossen, A., Gregor, K., Specht, J., “Enhancing dementia care capacity in Adult Day Services through staff training”, presentation at the National Dementia Care Conference, Atlanta, GA. September 11-14, 2006.

Specht, J., Yeggy, L., Bossen, A., “Serving Persons With Dementia From Diverse Populations In Adult Day And Respite”, presentation at the National Dementia Care Conference, Atlanta, GA. September 11-14, 2006.

Riesenberg, A., Yeggy, L., Specht, J., Bossen, A., ”Developing Mobile And Drop In Community Respite Programs”, accepted for presentation at the National Dementia Care Conference, Atlanta, GA. September 11-14, 2006.

Specht, J., Bossen, A., “Dementia Care: The evidence”, presentation to the School of Nursing and others, University of Iceland, Reykjavik, IS. May 23, 2006.

Specht, J., Bossen, A., “Trends, Diversity and Evaluating Outcomes in Adult Day Service Programs” day long educational program presented to the Iowa Adult Day Services Association Annual Spring Meeting, Des Moines, Iowa. March 23, 2006

Specht, J., Bossen, A., Benson-Vorwald, J., & Haverland, M., (2006) workshop presentation, “Investing in Home and Community Based Services for Persons with Dementia: Enhancing Capacity in Adult Day Services”. 2006 Joint Conference of National Council on the Aging & American Society on Aging, “Invest in Aging: Strengthening Families, Communities and Ourselves”. March 16-19, 2006, Anaheim, CA.

Walke, J., Bossen, A., “Update on Progress of the Iowa ADDGS Project”, presentation to the Iowa Commission for Elder Affairs, Des Moines, Iowa. February 10, 2006.

Bossen, A., “Update on AoA progress”, a presentation to Iowa Adult Day Association Board of Directors, January 9, 2006. Des Moines, Iowa.

AoA Grant, UI CON. (2005). A feature in the University of Iowa’s exhibit booth at the Iowa State Fair, August 2005, Des Moines, IA.

Specht, J., & Bossen, A. (2005). “CNA Training; Enhancing Quality of Life for Yourself and your patients”. Community College Instructor Update, Marshalltown, IA August 4, 2005. Certification Center, University of Iowa, Iowa Department of Inspections and Appeals, Iowa Valley Continuing Education Iowa Nurse Aide Curriculum and Testing Committees

Parks, J., & Bossen, A. (2005). A display, “Iowa’s Rural Alzheimer’s Demonstration Project AoA Grant: Enhancing capacity for dementia specific Adult Day Care and Respite for rural and emerging minority populations”. Building Iowa As A Healthy Community; The Governor’s Conference on Public Health Barn Raising V. Drake University, Des Moines, IA. July 28 & 29, 2005.

Hall, G., Staff program on Dementia. Friendship Village, Waterloo, Iowa. July 19, 2005.

Hall, G., Staff program on Dementia. Alzheimer’s Association, Waterloo, Iowa. July 19, 2005.

Yeggy, L. (2005). Blue Ribbon Award Nominee for Alzheimer’s Project in rural Iowa. July 13-18, 2005. Pilot’s Club International Annual Meeting, St. Louis, MO.

Bossen, A., & Bossen, K., (2005). A series of articles for Involvement magazine, the Heritage Area Agency on Aging newsletter; “Dementia and diversity; An African American health crisis”; a report from the conference “Aging, Dementia, & Diversity: Increasing Cultural Competency in the Aging Network”, University of Iowa College of Nursing, Iowa City, IA. July- August, 2005.

Hall, G., Training for ALF Certification. Iowa Healthcare Association, Des Moines, IA. June 14, 2005

Hall, G., Support group, Prairie Hills Assisted Living, Tipton Iowa. June 7, 2005.

Hall, G., Sexually Aggressive Behavior in Dementia. Iowa Association of Homes and Services for the Aged, Ames, Iowa. June 1, 2005.

Hall, G., Sexual Aggression in Long Term Care. Iowa Healthcare Association, Des Moines, IA. May 18, 2005.

Hall, G., Mapping Dementia, Dealing with Aggressive Behavior. University of Illinois at Springfield. May 17, 2005

Hall, G., 4/27 – Mapping Dementia. Geriatric Grand Rounds, Veterans Association Medical Center, Iowa City, IA. April 27, 2005.

Hall, G., The Person with Dementia in Your Practice, University of Iowa College of Dentistry faculty presentation. April 12, 2005.

Bossen, A. (2004). “Iowa’s AoA Alzheimer’s Grant: Results from an Adult Day & Respite Survey”. Iowa Adult Day & Respite Services Annual Meeting, Des Moines, IA March 17, 2005.

Hall, G., Bathing without a battle. Staff training in Fairfield, Iowa. October 13, 2004.

Hall, G., “Assessing persons with dementia who live-alone: the ARLA Tool”. Annual Aging Conference, University of Montana Center on Aging . October 19, 2004.

Hall, G., Non-pharmacologic Measures for Managing Problem Behaviors. Annual Psychiatric Nursing Conference, Iowa Veteran’s Home, Marshalltown, Iowa. October 10, 2004.

Hall, G., Nutritional Needs of People with dementia, Community Outreach program for the Alzheimer’s Association, Marion, Iowa. November 11, 2004.

Hall, G., WSUI – AM radio talk show, “Talk of Iowa” – Helping Elders with Dementia through the Holidays. November 10, 2004.

Hall, G., KXIC – AM radio broadcast, “The Roy Justice Show” – When Family is Faced with AD. November 1, 2004.

Hall, G., Nursing care of people with Dementia. Legacy Gardens, Iowa City Staff training. September 19, 2004.

Hall, G., “Assessing persons with dementia who live-alone: the ARLA Tool”. Nursing Research Conference, University of Missouri, Columbia, Mo. September 11, 2004

***Consultations of UI CON faculty;***

Hall, G., Highland Park, Williamsburg, Iowa. July 1, 2005

Specht, J., Methodist Manor, Storm Lake, IA. Regarding conducting a feasibility study for Adult Day Care servicing ethnic diverse populations and dementia. June 30, 2005

Specht, J., & Bossen, A., Prairie Hills, Tipton, Iowa. May 19, 2005.

Hall, G., Hospice of the Valley, topic; Advanced Alzheimer’s Project. March 18, 2004

Specht, J., G &G Living Centers, Inc. in Guttenberg, IA. Regarding environmental modifications and programming for Day Care for Older Adults including those with dementia. March 17, 2005.

***Manuscripts***

“Integrating dementia skills into practice: More than a didactic process”. Specht, J., Bossen, A., Zimmerman, B., Russell, J.

“A case study of a client with atypical dementia in rural Iowa”. Specht, J., Bossen., A., Yeggy, L.

Specht, J., Bossen, A., Zimmerman, B., Russell, J., (in preparation, fall 2007) “Enhancing capacity in Adult Day Services in caring for clients with dementia: The role of the nurse”.

Specht, J., Bossen, A., Zimmerman, B., Russell, J., (in preparation, fall 2007) “Video observations as an educational tool: Dementia training enhancement”.

Specht, J., Bossen, A., Zimmerman, B., Russell, J., (in review, winter 2006) “Nurse Care Manger, Community dementia specialist: Role description & caregiver outcomes evaluation”, Alzheimer’s Care Quarterly.

Hall, G., Specht, J., Bossen, A., Zimmerman, B., (in submission, summer 2006) “Living alone with dementia: A quick assessment for knowing when to intervene”, Journal of Gerontologic Nursing.

***National recognition of research significance***

In 2004 Dr. Yvonne D. Eaves, PhD, RN, Assistant Professor currently at University of Alabama, Birmingham School of Nursing, was awarded a 5 year KO1 grant from NIA titled “A Caregiving Intervention for Rural African Americans”. The instruments being used are a modified version of those developed and used by the Iowa AoA grant. She was in contact with the PI and Co-PI for technical assistance.

**Products**

**“Summary report for the Iowa Alzheimer’s Task Force 2007** **from the Iowa Alzheimer’s Demonstration Projects”**, a report for the State convened Alzheimer’s Task Force, September 2007.

**Dementia Training Series** (*see attached outlines, Appendix A*)

This training series was developed based on the feedback from the ADS across the state as to what they felt their educational needs were. Topics were integrated into larger topical areas with state rules and regulations and culturally competent components added as relevant. All ADS participating as intervention sites were given a notebook with the power point presentation, handouts and individualized comments from staff input to assist in implementation of what they learned. In addition, each agency was given a training handbook, “Teaching Dementia Care: Skill & Understanding”, by Nancy Mace, John Hopkins University Press, 2005, as a resource for future dementia care issues and training.

I. Communication: The key to quality dementia care

II. Meaningful activities for the person with dementia: Activities & tools in ADS

III. Behavior management: Making the most of the environment

IV. Leadership in ADS: Translating research into practice, leadership and evaluation of staff

**Video taping/ observational recording** *(see Appendix B)*

**Memory Loss Nurse Specialist CM record of activity template** *(see Appendix C)*

Materials from partner agencies were translated into Spanish; being used by Heritage Area & Siouxland Aging region, (previously submitted).

**Appendices**

**Appendix A**

**Training 1 Outline**

**Communication: The Key to Quality Dementia Care**

“Creating enjoyment in your job while creating a positive, safe and stimulating day for participants.”

*Objectives*

1. Discuss the impact of communication & the client/ patient outcomes
2. The PLST model
3. Discuss common behaviors, interventions, & potential strategies to teach interventions

A. Communication …..

Definition, what it is, what it does.

B. Verbal & Nonverbal communication

What are they and how are they utilized in communicating in the person with dementia?

C. Influence of dementia on communication

Losses that occur in dementia

D. Global Deterioration Scale (GDS)

What it is and shy it’s important to understand.

E. Early Stage Communication Losses (GDS score of 3-4)

F. Middle Stage Communication Losses (GDS score of 4-5)

G. Late Stage Communication Losses (GDS score of 6-7)

H. Essential Communication Components

I. Focus on the person

**P** - Positive approach

**E** - Empathy for what the individual is experiencing

**R** - Respect for him/her as an individual

**S** - Sincerity in your approach

**O** - Openness

**N** - Nonjudgmental attitude

H. Selected Strategies to Promote Communication

J. Roles: The your role in dementia care is often one of the most intimate, important and complex. Even when you don’t know what to do, often just your presence makes a difference.

Be a magician- to know the tricks re: individual behavior

Be a detective- clues to unmet needs

Be a carpenter- build individual CP, use tools & resources wisely

Be a jester- have a ready sense of humor & spread joy

K. Person Centered Care

All behavior has meaning; behavior represents understandable feelings and needs, even if the individuals are unable to express the feelings or needs. Identifying and responding to those feelings and needs will reduce the incidence of behavioral symptoms.

L. Progressively Lowered Stress Threshold or PLST Model

What this theory is and why it’s useful. Most troublesome symptoms 4 categories

M. Categories of BPSD

1. Behavioral symptoms (observed)
2. Psychological symptoms (Interview)
3. Excess Disability
4. Conditions characterized by increased functional and behavioral limitations or disability that are not directly attributable to the underlying pathophysiology
5. These conditions are generally reversible and many can be prevented,……

N. Six causes of excess disability

O. Six principles of care

1. *Maximize safe function by supporting all losses in a “prosthetic” manner,….*
2. *Provide unconditional positive regard*
3. *Use behaviors to gauge activity and stimulation levels*
4. *“Listen" to behaviors*
5. *Modify the environment to support losses*
6. *Provide on-going assistance to informal caregivers*

P. Interventions strategies & principles

1. Task breakdown
2. Humor
3. Re-approaching
4. All activities therapeutic
5. Alternate periods of rest with periods of higher stimuli
6. 2 “How” questions of management
7. 11 W’s of situation

Q. Effective Milieus

Music therapy, Validation therapy, Multisensory therapy- massage, therapeutic touch, aromatherapy, Pet therapy, Therapeutic recreation therapy, Story telling, Exercise or movement therapy, Environmental manipulation

R. General principles;

People with ADRD & their CGs are still people with the same needs as all of us. They need;

* To know they are loved
* To feel good about themselves
* To be respected & treated with dignity
* To have approval of others important to them

They also need;

* To be stimulated in body, mind and spirit
* To feel secure
* To be included not alienated
* To celebrate the joy of life to be needed
* To have physical contact with those they love

- Elbert Cole, 1998

**Training 2 Outline**

**Meaningful activities for the person with dementia: Activities & tools in ADS**

*Objectives*

1. To understand that each staff person has a role in implementing meaningful activities

2. To be able to define what a meaningful activity is

1. To understand the importance of meaningful activities for persons with dementia
2. To understand ways to use GDS and MMSE information in planning care for persons with dementia

A. Review basic facts from the Communication Module

B. Defining “TOOLS” of assessment

MMSE, GDS, FA-II, Clock Drawing

Early/Middle/Late Stages – correlate the GDS/MMSE scores with the levels

Define the 5 types of activities

C. MMSE or the Mini Mental Status Exam

D. GDS or Global Deterioration Scale- defining characteristics and remaining abilities

Stages 1 & 2

Stage 3: Mild Cognitive decline (early confusional stage)  
Stage 4: Moderate cognitive decline (late confusional)

Stage 5: Moderately severe cognitive decline (early dementia)

Stage 6: Severe cognitive decline (middle dementia)

Stage 7: Very severe cognitive decline (late dementia)

E. Clock Draw test

F. FA 2 or Functional Assessment 2

G. What is a “meaningful activity”?- review of new CMS guidelines & how they pertain in ADS

H. Considerations & components

I. Opportunities for therapeutic activities

Activities of daily living, housekeeping, meal, table preparation, family visits, religious events, holidays, social gatherings

J. Planning activity programs

K. Overstimulation vs. sensory deprivation: Balancing activities

L. Benefits

M. Barriers for a person’s participation

Pain & discomfort

N. Group dynamics

O. Examples; Life stories/ Memory Boards, Time Slips

P. Outcomes and how to assess them; What is success?…process not just outcome

**Training 3 Outline**

**Behavior management: Making the most of the environment**

This session was comprised of mostly staff activities based on the first two learning didactic sessions. Real client situations, activities calendars, and care plans were used as examples (without names and under rules of confidentiality and privacy). Participants were given “homework” either as individuals or small groups to go back to their practice settings and investigate and try, then report back to the larger group.

*Objectives;*

1. Discuss pain as it related to behaviors
2. List at least 3 other types of dementia and discuss how each type impacts behavior concerns
3. Outline the considerations in acute behavior intervention
4. Discuss considerations in a behavior management plan

A. The meaning of Behaviors

B. Person Centered Care

C. Review of PLST model; Six principles of care, sources of environmental stress- senses; six causes of excess disability

D. Assessing the client

* S is for Sleep disorders
* P is for Problems with eating or feeding
* I is for Incontinence
* C is for Confusion
* E is for Evidence of falls
* S is for Skin breakdown

E. Assessing discomfort

F. 8 Methods for dealing with unwanted behavior

G. Acute aggressive/ protective behaviors- approaches & key components

* When aggressiveness occurs

H. Developing a facility prevention and intervention plan

**Leadership Training**

**Leadership in ADS: Translating research into practice, leadership and evaluation of staff**

This session was offered to the directors of the interventions sites at an off location, after hours session. The Directors were invited to a session for discussion away from their supervisors/ owner so communication could be more honest and meaningful.

*Objectives*

A. Recognition of participation and support by center administrators/ owners

B. Review the training- feedback, by session- what was effective

C. Discussion of the role of leadership in implementation of Best Practices & barriers to attaining them; how to evaluate whether staff behavior changes, implementing changes and empowering staff

D. Identifying measuring outcomes- Celebrating successes

Handout:

AoA ADS Managers Training

Outcomes of Best Practices Implementation

Staff will demonstrate;

* Respectful care
* Positive participant/ staff interactions
* Improved satisfaction with job and ability to handle situations
* Less expressed job related stress
* Identification of and action taken to minimize/ extinguish triggers of difficult behaviors
* Less staff turnover
* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Participants will exhibit;

* Active engagement every day
* Diminished difficult behaviors
* Increased expression of enjoyment of life
* Minimized excess disability
* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
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Overall the center will experience;

* Calmer environment
* Family satisfaction
* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
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**Appendix B**

**Video/ Observational Recording Form**

**Agency Name: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Date \_\_\_\_\_\_\_ \_\_\_\_**

**Participant initials:\_\_\_\_\_\_\_\_\_** **Client or Staff (circle)**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Time Start/Stop** | **Name** | **Activity of staff** | **Level of engagement**  **of client** | **Context/ comments** |
|  |  | **1 2 3 4 5 6 7** | **1 2 3 4 5** |  |

**Codes:**

|  |  |
| --- | --- |
| **Activity of Staff** | **Level of engagement** |
| 1= 1 on 1 | 1= spontaneous participation |
| 2= group | 2= verbal cueing |
| 3= indirect care | 3= verbal cueing and demonstration |
| 4= ADL assist | 4= verbal cueing & physical prompting |
| 5= interacting w/other staff | 5= Not applicable |
| 6= interacting w/other client |  |
| 7= self occupied (office work, cleaning environment) |  |

**Demeanor of staff; POSITIVE AFFECT, NEGATIVE AFFECT, MOOD, & BEHAVIORS**

|  |  |  |  |
| --- | --- | --- | --- |
| **POSITIVE AFFECT** | **Present** | **Absent** | **Not Applicable** |
| Warmth and tenderness | 1 | 2 | 3 |
| Attention (focusing on the resident’s needs and wishes) | 1 | 2 | 3 |
| Humor | 1 | 2 | 3 |
| Approving comments/complements | 1 | 2 | 3 |
| Mind-read positive | 1 | 2 | 3 |
| Positive touch | 1 | 2 | 3 |
| Paraphrase/reflect | 1 | 2 | 3 |
| Compromise | 1 | 2 | 3 |
| Validation | 1 | 2 | 3 |
| Sensitive for reactions/calm | 1 | 2 | 3 |
| Showing respect | 1 | 2 | 3 |
| Informing/limitations | 1 | 2 | 3 |
| **NEGATIVE AFFECT** | **Present** | **Absent** | **No Applicable** |
| Scream | 1 | 2 | 3 |
| Rejection | 1 | 2 | 3 |
| Ignoring/not responding to questions | 1 | 2 | 3 |
| Unintelligible talk/belittling | 1 | 2 | 3 |
| Mind-read negative | 1 | 2 | 3 |
| Put down/devaluing | 1 | 2 | 3 |
| Turn off | 1 | 2 | 3 |
| Criticize | 1 | 2 | 3 |
| Not tracking | 1 | 2 | 3 |
| Invalidation | 1 | 2 | 3 |
| Demanding/domineering | 1 | 2 | 3 |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **MOOD (tone of voice)** | **Present** | **Absent** | **Neutral** | **Not able to tell** |
| Happy | 1 | 2 | 3 | 4 |
| Sad | 1 | 2 | 3 | 4 |
| Tired/listed | 1 | 2 | 3 | 4 |
| Hostility | 1 | 2 | 3 | 4 |
| Threats | 1 | 2 | 3 | 4 |

|  |  |  |  |
| --- | --- | --- | --- |
| **BEHAVIORS** | **Present** | **Absent** | **No Applicable** |
| Glowering | 1 | 2 | 3 |
| Physical intimidating | 1 | 2 | 3 |
| Pounding fists | 1 | 2 | 3 |
| Sour look | 1 | 2 | 3 |
| Rolls eyes dramatically | 1 | 2 | 3 |
| Sigh deeply | 1 | 2 | 3 |
| Exaggerated gasp | 1 | 2 | 3 |
| Withdrawal | 1 | 2 | 3 |
| No eye contact | 1 | 2 | 3 |
| Give multiple instructions at a time | 1 | 2 | 3 |
| Give unclear explanations | 1 | 2 | 3 |

Positive affective definitions:

* Approve-respondent favors one’s attributes, actions, or statements.
* Assent-listener says ‘yeah’, nods head, etc. to indicate ‘I’m listening’ or facilitate conversation.
* Attention-listener maintain eye contact for at least three seconds.
* Compromise – a negotiation of mutually exchanged behaviors.
* Humor –light-hearted humor, not sarcasm.
* Mind-read positive-statement that infers or assumes a positive attitude or feeling on the part of the other.
* Paraphrase/reflect-a statement that mirrors or restates statement of the other which has been previously expressed within the negotiation.
* Positive physical touch- a statement that conveys “I” or “we” are not responsible for this problem.

Negative affect definitions:

* Command-direct request for immediate action fulfillable within negotiation.
* Criticize-hostile statement of unambiguous dislike or disapproval of a specific behavior, Non-neutral voice tone.
* Mind-read negative-statement that infers or assumes a negative attitude or feeling on the part of the other.
* Not tracking-listener does not make or maintain eye contact within three seconds.
* Put down-a comment intent to hurt, demean or embarrass others.
* Turn off-nonverbal gestures that communicate disgust, displeasure, disproval, or disagreement. Can also indicate negative voice tone which statements of positive or neutral content.
* Unintelligible talk-inaudible or ‘incomplete’ speech units.

**Appendix C**

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
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|  |  | |  | |  | | | | |  | | | | |  | | |  | | | | | | | | **Memory Loss Nurse Specialist** | | | | | | | |
| **County Report** | | |  | |  | | | | |  | | | | |  | | |  | | | |  | | | |  | | |  | | |  | |
|  | **# New** | | **Referral** | | **Referral** | | | | | **LA** | | | | | **# CR or** | | | **Crisis** | | | | **GDS on** | | | | **Exit** | | | **date of f/u** | | | **Outcome** | |
|  | **clients** | | **Source** | | **Date** | | | | | **Y/N** | | | | | **CG calls** | | | **Y/N** | | | | **Admit** | | | | **Reason** | | | *intake for new/* | | | *(Narrative comments)* | |
|  |  | |  | |  | | | | |  | | | | |  | | |  | | | |  | | | | *Date* | | | *date of f/u* | | |  | |
| ***Benton*** |  | |  | |  | | | | |  | | | | |  | | |  | | | |  | | | |  | | |  | | |  | |
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| ***Cedar*** |  | |  | |  | | | | |  | | | | |  | | |  | | | |  | | | |  | | |  | | |  | |
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| ***Iowa*** |  | |  | |  | | | | |  | | | | |  | | |  | | | |  | | | |  | | |  | | |  | |
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| ***Johnson*** |  | |  | |  | | | | |  | | | | |  | | |  | | | |  | | | |  | | |  | | |  | |
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| ***Jones*** |  | |  | |  | | | | |  | | | | |  | | |  | | | |  | | | |  | | |  | | |  | |
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| ***Linn*** |  | |  | |  | | | | |  | | | | |  | | |  | | | |  | | | |  | | |  | | |  | |
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| ***Washington*** |  | |  | |  | | | | |  | | | | |  | | |  | | | |  | | | |  | | |  | | |  | |
|  |  | |  | |  | | | | |  | | | | |  | | |  | | | |  | | | |  | | |  | | |  | |
| **Adult Day Services & Respite use** | | | | | | | | | | | |  | | | |  | | | |  | | | |  | | |  |  | | |  | |  | |
|  | **Undupl *(new)*** | | | **# using** | | | **Undupl *(new)*** | | | | | **# using** | | | | **Reason code** | | | | **# referred to** | | | | **# referred to** | | | **# referred to** | **# referred to** | | | **CM mtg** | | **Other mtgs** | |
|  | **ADS clients** | | | **ADS** | | | **Respite** | | | | | **R** | | | | **for DC** | | | | **ADS by MLNS** | | | | **ADS by CM** | | | **R by MLNS** | **R by CM** | | |  | | *name* | |
| **Benton** |  | | |  | | |  | | | | |  | | | |  | | | |  | | | |  | | |  |  | | |  | |  | |
| **Cedar** |  | | |  | | |  | | | | |  | | | |  | | | |  | | | |  | | |  |  | | |  | |  | |
| **Iowa** |  | | |  | | |  | | | | |  | | | |  | | | |  | | | |  | | |  |  | | |  | |  | |
| **Linn** |  | | |  | | |  | | | | |  | | | |  | | | |  | | | |  | | |  |  | | |  | |  | |
| **Jones** |  | | |  | | |  | | | | |  | | | |  | | | |  | | | |  | | |  |  | | |  | |  | |
| **Johnson** |  | | |  | | |  | | | | |  | | | |  | | | |  | | | |  | | |  |  | | |  | |  | |
| **Washington** |  | | |  | | |  | | | | |  | | | |  | | | |  | | | |  | | |  |  | | |  | |  | |
| **Code for discharge from ADS/R** | | | | | | | | | | | | | |  | | |  | | | |
| 1= death | | | | | | | | |  | |  | | |  | | |  | | | |
| 2= placement (note NH = 2.1; AL= 2.2) | | | | | | | | | | |  | | |  | | |  | | | |
| 3= Behavior change, provider (incompatible with ADS/R- add note) | | | | | | | | | | | | | | | | | | | | |
| 4= Client/ family decision- add note | | | | | | | | | | |  | | |  | | |  | | | |
| 5= move away | | | | | | | |  |  | |  | | |  | | |  | | | |
| 6= transportation | | | | | | | |  |  | |  | | |  | | |  | | | |
| 7= unable to find adequately trained R provider | | | | | | | | | | | | | |  | | |  | | | |
| 8= staffing issues - add note | | | | | | | | |  | |  | | |  | | |  | | | |
| 9= Behavior change- client (add note) | | | | | | | | | | |  | | |  | | |  | | | |
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| **Activity/ Education/ Coordination Report** | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| **Trainings provided** | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| **Agency name** | | **County** | | | | **Activity** | | | | | | | **Topic** | | | | | | **Number attending** | | | | **Type *(RN,NA, etc)*** | | **Who initiated?** (Agency, individual, MLNS, cold call) | | | | |
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| **Respite activity** | |  | | | |  | | | | | | |  | | | | | |  | | | |  | |  | | | | |
| **County of client** | | **Type** *(In home or Institutional)* | | | | **Payment source** | | | | | | | **Total hours month** | | | | | | **Hrs/ ct** | | | | **Crisis? Y/N** | | **Training done** | | | | |
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| **New R Centers or individual R providers** | |  | | | |  | | | | | | |  | | | | | |  | | | |  | |  | | | | |
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| **ADS Activity - consultations** | |  | | | |  | | | | | | |  | | | | | |  | | | |  | |  | | | | |
| **Agency** | | **County** | | | | **Activity** | | | | | | | **Outcome** | | | | | | **# cts seen** | | | | **GDS** | | **Hours/mo** | | | | |
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| **Narrative;** Any comments or concerns. Nursing services / activities not covered elsewhere. | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
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**References used in developing training**

Boettcher, I., Kemeny, M.S., DeShon, R., Stevens, A., (2004). *A system to develop staff behaviors for person centered care*. Alzheimer’s Care Quarterly. 5(3): 188-196.

Buettner LL. Simple Pleasures: a multilevel sensorimotor intervention for nursing home residents with dementia. *American Journal of Alzheimer's Disease.* Jan-Feb 1999; 14(1):41-52.

Colling KB, Buettner LL. Simple pleasures: Interventions from the Need-Driven Dementia-Compromised Behavior Model. *Journal of Gerontological Nursing.* 2002; 28(10):16-20.

Gitlin LN, Liebman J, Winter L. Are environmental interventions effective in the management of Alzheimer's disease and related disorders: A synthesis of the evidence. *Alzheimer's Care Quarterly.* 2003; 4(2):85-107.

Hall, G.R: Caring for people with Alzheimer’s disease using the conceptual model of progressively lowered stress threshold in the clinical setting. *Nursing Clinics of North America.* 1994; 29:129-141.

Hall, G. and Buckwalter, K: A conceptual model for planning and evaluating care of the client with Alzheimer's disease. *Archives of Psychiatric Nursing.* 1987; 1: 399-406.

Kelley, L.S. & Lankin, J.A: Role supplementation as a nursing intervention for Alzheimer’s disease: A case study. *Public Health Nursing*. 1988; 5: 146-152.

Folstein, M.F. & Folstein, S.E: Neuropsychiatric assessment of syndromes of altered mental state. In W.R. Hazard, E.L. Bierman, J.P. Blass, W.H. Ettinger, Jr., J.B. Halter, & R. Andres. (Eds.), Principles of Geriatric Medicine and Gerontology (3rd Edition, pp 221-228). New York: McGraw-Hill, 1994.

Reisberg, B., Sclan, S.G., Franssen, E., Klugger, A., & Ferris, S: Dementia staging in chronic care populations. *Alzheimer’s Disease and Associated Disorders*. 1994; 8: S188- S201.

Groff, R.L. FA II Procedure Manual. Prepared by Hall Simonton Bell, Des Moines, IA. 1997: Unpublished

Lawton, M.P., and Brody, E.M: Assessment of older people: Self-maintaining and instrumental activities of daily living. *The Gerontologist*. 1969; 9: 179-186

Mace, N., Coons, D., & Weaverdyck, S.(2005). *Teaching dementia care; Skill and understanding*. Baltimore & London: The Johns Hopkins University Press.

McGilton, K. S., (2004). Relating well to persons with dementia: A variable influencing staffing and quality of care outcomes.  *Alzheimer’s Care Quarterly.* 5(1): 71-80.

Otigara, A. (2000). Understanding the Language of Behaviors. *Alzheimer’s Care Quarterly.* 1(4):89-92.

Pietro, M.J., (2002). Communicate effectively with persons with Alzheimer’s Disease” A call for action. *Alzheimer’s Care Quarterly*. 3(2): 157-164.

Pietro, M.J., & Ostuni, E., (1997). *Successful communication with Alzheimer’s Disease Patients: An in-service manual*. Boston: Butterworth-Heimemann.

Smith M, Buckwalter K, Mitchell S. Acting up and acting out: Assessment and management of aggressive and acting out behaviors. In: Smith M, Buckwalter K, Mitchell CM, eds. *The Geriatric Mental Health Training Series*. New York, NY: Springer Publishing Company; 1993.

Wallace, M., & Fulmer, T., (2007) Fulmer SPICES: An overall assessment tool for older adults. <http://www.hartfordign.org>

Talerico & Evans, (2000) Making sense of aggressive/ protective behaviors in persons with dementia. Understanding Behaviroal Symptoms; *Alzheimer’s Care Quarterly* 1(4), 77- 88.

Teri & Logsdon, (1991). "Identifying Pleasant Activities for Alzheimer's Disease Patients: The Pleasant Events Schedule-AD", *Gerontologist* 1991

**References used in preparing video taping evaluation forms**

Gallagher-Thompson, D., Dal Canto, P.G., Darnley, S., Basilio, L.A., Whelan, L., & Jacob, T. (1997). A feasibility study of video taping to assess the relationship between distress in Alzheimer’s disease caregivers and their interaction style. *Aging & Mental Health*. 1(4): 346-355.

Heyman, R., Weiss, R., & Eddy, M., (1995). Marital interaction coding system: Revision and empirical evaluation. *Behavioural Research & Therapy*. 33(6): 737-746.

Heyman, R., & Vivian, D., (2000). RMICS: Rapid Marital Interaction Coding System. Retrieved from [www.psy.sunysb.edu/marital/](http://www.psy.sunysb.edu/marital/)

Mayhew, P., Acton, G., Yauk, S., & Hopkins, B., (2001). Communication from individuals with advanced DAT: can it provide clues to their sense of self-awareness and well-being? *Geriatric Nursing*. 22(2): 106-110.

Skovdahl, K., Kihlgren, A., & Kihlgren, M., (2004). Dementia and aggressiveness: stimulated recall interview with caregivers after video-recorded interactions. *Journal of Clinical Nursing*. 13: 515-525.

Smallwood, J., Irvine, E., Coulter, F., & Connery, H., (2001). Psychometric evaluation of a short observational tool for small-scale research projects in dementia*. International Journal of Geriatric Psychiatry*. 16: 288-292.