

# **SUMMARY REPORT FOR THE IOWA ALZHEIMER'S TASK FORCE 2007 FROM THE IOWA ALZHEIMER'S DISEASE DEMONSTRATION PROJECTS**

**AOA GRANT #90AZ2366**, "BUILDING A SEAMLESS DEMENTIA-SPECIFIC SERVICE DELIVERY SYSTEM FOR RURAL AGED", (1999-2004)

**AOA GRANT #90AZ2774**, "ENHANCING CAPACITY FOR DEMENTIA SPECIFIC ADULT DAY CARE AND RESPITE FOR RURAL AND EMERGING MINORITY POPULATIONS", (2004-2007).



**The AoA Alzheimer's Demonstration Grants offered an excellent opportunity for collaboration & sharing between various state and public agencies that strengthened & expanded services for the benefit of its most vulnerable citizens.**

Iowa Department of Elder Affairs with the University of Iowa College of Nursing

AoA Rural Iowa Alzheimer's Demonstration Project 2005

Memo To: Iowa Alzheimer's Disease Task Force  
From: Iowa's AoA Alzheimer's Disease Demonstration Grant collaborating partner, the University of Iowa College of Nursing, John A. Hartford Center for Geriatric Nursing Excellence

Dear Alzheimer's Task Force member,

First of all we commend the State Legislature and the Iowa Department of Elder Affairs for their establishment of this Task Force. We commend you for your commitment and time in serving on this committee. The needs of persons with dementia and their caregivers are great. Improving services and preparing a plan for the future is crucial in establishing the network that is and will increasingly be essential in adequately managing the care needs of our fellow Iowans affected by dementing illnesses. Developing evidenced based intervention strategies will allow Iowa to be fiscally prepared and act responsibly in developing for the complex needs of Alzheimer's disease and related dementias, especially as our population ages.

The following is an outline of the earnest work of many people, publicly and privately employed, in attempting to establish sustainable, evidenced-based care for persons with dementia and their caregivers across the state. These are the findings and products enabled through a grant from the Administration on Aging over the past 7 years. We are providing it to you to use as you see fit; a guide for new programs and strategies, for understanding of systems that exist and possible barriers, and potentially as replicable models for future use.

We share a common commitment to improving care for persons with dementia. We offer any assistance in providing research, recommendations, consultations at your request. Thanks you for serving this vulnerable population.

Respectfully,

Janet K. Specht, PhD, RN, FAAN

Ann Bossen, MSN, RN, BC

**AoA Grant #90AZ2366**, "Building a Seamless Dementia-Specific Service Delivery System for Rural Aged", (1999-2004). UI CON Project Personnel: Principal Investigator, Janet Specht; Co-PI Geri Hall, Project Coordinator, Ann Bossen; Consultants; Kathleen Buckwalter, Meridean Maas, Marianne Smith, Toni Tripp-Reimer.

**AoA Grant #90AZ2774**, "Enhancing capacity for dementia specific Adult Day Care and Respite for rural and emerging minority populations", (2004-2007). UI CON Project Personnel: Principal Investigator, Janet Specht; Co-PIs Geri Hall & Ann Bossen; Consultants; Kathleen Buckwalter, Meridean Maas, Lisa Kelley.

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The charge of the Alzheimer's Task Force is in line with many of the issues we have addressed through the AoA Iowa Alzheimer's Disease Demonstration Grants. We have compiled for your use a description of and results from our efforts during this time as well as a summary of lessons learned and recommendations as to service needs of persons with dementia and their families in the state. Further details or resources are available upon request. Attached at the end of this paper are: the position paper developed by the Statewide Committee, the tool, Assessment for Risk of Living Alone (ARLA), the ADS survey results, and the journal article on recommendations for educational preparation by Buckwalter & Maas, 2006.

The Iowa Department of Elder Affairs, in collaboration with the University of Iowa College of Nursing, 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 a grant from the Administration on Aging. This grant tested out several models of care (dementia nurse care manager, memory loss nurse specialist, "People Living Alone Need Support" (PLANS), varying models of respite care), surveyed agencies and service providers in regard to how they provide services for persons with dementia, and provided 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.

The collaboration with the University of Iowa College of Nursing, John A. Hartford Center for Nursing Excellence is completed, and it is noteworthy that an AoA grant was awarded again to DEA (July 2007), which continues under the same concepts and foci as previous grants developed and implemented by the UI CON, minus the nursing aspects (NCM & MLNS). Though it is unfortunate not to have continued support for the innovative nursing roles, which would set Iowa as a leader in geriatric care, the intent initiated by the UI CON of providing expanded services and support of person with dementia and their caregivers is continuing. These grants were demonstration projects with research methods used for evaluation and the knowledge gained give us valuable insights into what works in community settings. It is important that Task Force recommendations are formulated from the evidence base of dementia care and lessons learned from the previous grants, guided by current evidence, be available to assist in guiding future planning.

## **OVERALL RECOMMENDATIONS**

Given the premises that:

- If persons with dementia and their caregivers are given support, adequate diagnosis and care management, they are able to be maintained in their home longer
- Well-being and stress of care givers can be address and mediated to some degree by adequate support and education
- There is a lack of awareness of and knowledge about dementia, the disease process and management of issues
- Many of the disturbing behavior issues connected with dementia are a result of inappropriate care or management of the manifestations of the disease
- Dementia care costs can be reduced by adequately providing services and support to care givers and clients with dementia by preventing premature institutionalization

## **RECOMMENDATIONS**

1. Promote education and training of professionals and paraprofessionals in geriatric mental health services, especially dementia care. This can be accomplished in several ways;
  - a. Ensure state supported education (community college & university) to be mandated to offer dementia specific courses in their curriculums, throughout the state at affordable costs, to all health care providers curricula.
  - b. Offer certification programs to train respite providers & paraprofessionals to care for persons with dementia.
  - c. Encourage and fiscally support geriatric higher education initiatives in State institutions.
2. Improved reimbursement for dementia clients in ADS & R to be equitable to reimbursement for the mentally retarded/ developmentally disabled (MRDD) population rates and to include travel time for respite, which is especially critical in rural areas.
3. Foster programs that promote awareness of services available through PSAs and other means (for example, educate the public of the benefits of ADS & R care).
4. Sponsor programs/ technical support that foster development of community based/ driven initiatives for adult day programs, respite centers, "recreation clubs" for the elderly, support

services like friendly visitors, faith-based action plans, minority competence and service provision.

5. Advocate for innovative demonstration initiatives in dementia care environments and work toward provisions in Iowa State code to allow for new models of care that are evidenced based.
6. Provide funding for and mandate integration of a "memory loss nurse specialist or dementia nurse care manager into each AAA to work in the CMPFE system to be a resource and referral source for formal and informal caregivers. Families dealing with dementia often are frail and elderly, experiencing multiple chronic illnesses. Because of this, nurses, when adequately trained in the specifics of dementia, can provide more holistic health care for and with the client and families to effect more positive outcomes than current case management.
7. Transportation, especially assisted transportation is urgently needed in rural areas provide access to services that do exist, and to support utilization of services that are developed. Financial assistance needs to be enough to not only pay for the services, but include the transportation needed to access the service.
8. Efforts need to address availability and quality of diagnostic services, focusing on early identification, is especially needed in rural areas.
9. There is a need to develop services that address the needs of persons with early onset as they often fall through the gap because of their age. They need access to appropriate diagnostic services, support groups for the person with the disease & CG, services focused on interventions for the person with the disease at their current cognitive level, and caregiver training.
10. Education for ADS & R needs to be provided to develop programs and capacity to serve diverse programs including brain injured, developmentally disabled, and persons with dementia, specifically on programming to integrate these populations. (Based on evidence presented by experts at the IADSA 2006 conference, sustainability depends on serving blended populations, not specifically targeted populations like dementia).
11. Involve individual community in designing and developing in dementia services for their areas (based on the PLANS model).
12. Review/ revise rules and regulations for dementia specific education and training to;
  - a. Ensure that dementia specific training is required in every level of service provision (EGH, AL, ADS, and NH).
  - b. Require specific content rather than number of hours of training

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- c. Is based in current evidenced based dementia care and recommended guidelines (see attached Maas & Buckwalter article)
- d. Build in positive incentives for facilities/ programs that exceed the minimal requirements (Illinois model).

## **SCOPE OF THE PROBLEM** *(from AoA grant 2 proposal)*

### **Demographic information**

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). Eliminating the option of paying for in-home services, at least 1/3 of these households have incomes of less than \$10,000 (<http://www.state.ia.us/elderaffairs/Documents/IowaFacts.pdf>, 2001).

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](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](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.

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

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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.

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 diversify. 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](http://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](http://www.nadsa.org/press_room/facts_stats.htm)).

### **AoA Grant 1: “Building a Seamless Dementia-Specific Service Delivery System for Rural Aged”, 1999-2004**

Participating agencies: the Iowa Department of Elder Affairs, University of Iowa College of Nursing & Center on Aging, Generations AAA, Heritage AAA, Siouxland AAA, Elder Services, Inc., Alzheimer's Associations – Big Sioux Chapter, East Central Iowa Chapter, Greater Iowa Chapter & Aging Resources of Central Iowa AAA (years 1,2) .

The Iowa AoA Demonstration project was an effort of the State of Iowa to develop community based service options for persons with dementia and their informal caregivers. The grant was a combined effort of AAA and Alzheimer's Association chapters in regions identified as pilot areas along with agencies within their service provider networks. The grant engaged agency ownership through having the agencies design and direct the specific program foci in their area, though the conceptual framework and model for the service delivery demonstration of a dementia specific nurse care manager was consistent. Each AAA area was administered differently, had a different numbers of counties, each was very rural; contracts case management services and waiver delivery differently, and had different

services and service gaps. The UI CON was contracted to do the implementation and evaluation of the projects.

This project demonstrated a nurse care managed service delivery system for persons with Alzheimer's Disease and Related Dementias (ADRD) and their families along with a structured community development strategy to increase access to and use of community-based support services. By design, the project built upon and expanded successful dementia service models to better identify and deliver services to persons with ADRD. This approach used community members to identify the unique strengths, limitations, needs, and opportunities for growth within the region served by the AAA.

### **ENROLLMENT**

Data were collected for three years. There were 249 client dyads enrolled; 66% were identified as not having previously been in the CMPFE system. Individuals served throughout the grant:

- Total *enrolled*\* in 4 years = 318  
(includes both frail couples and people living alone)  
Cedar, Iowa, Johnson, Washington 92  
Cherokee, Ida, Monona, Plymouth, Woodbury 114  
Clinton, Muscatine, Scott 112

\*This total does not include families served through the Alzheimer's resource line number, educational offerings, MLNS outreach, Support groups, DIALZ, or other direct client contacts where consultation, education and services are offered.

### **NURSE CARE MANAGER (NCM)**

Conceptualization of the role of the NCM was to assist and empower the caregiver (CG) and person with dementia or "care recipient" (CR) to manage the circumstances surrounding the manifestations of the disease using a variety of established dementia management strategies (Algase, et al 1999; Buckwalter & Hall, 1987; Hall 1994; Kelley & Lankin, 1988; Kowlanoski, 1999; Noelker, 2001). The goal was to maintain persons with dementia safely in their homes as long as they and their families chose by connecting them with appropriate services and support. The NCMs were responsible for care recipient (CR) and caregiver (CG) outcomes. The knowledge of the NCMs helped them identify in both CG and CR conditions which exacerbated the dementia process or impeded effective care provision or quality of life for the clients, a contribution unique that nurses could add to the existing

case management system. The CM system is currently provided mainly by professionals from disciplines other than nursing with a major focus on coordination of services rather than provision of direct services.

Evaluating the NCM model compared outcomes of the CG and CR to a similar group that did not have a dementia nurse care manager. When compared CGs of clients who had an NCM to those under the current case management system, CGs for the NCM group were substantially more positive than for the traditional care (control) group in their level of stress, well-being and endurance potential (ability to care for someone) than the other group. In addition, even though the physical functioning of the person with dementia declined (as in the expected course of the disease) the amount of CG stress did not increase in the NCM group. In addition, measured through anecdotal data, CGs reported being able to keep their loved one at home for much longer, sometimes delaying institutionalization for over a year.

NCMs were able to identify then advocate with physicians to treating underlying causes and diseases that had been undiagnosed or not under control (for example, hypertension or diabetes, or ineffective/toxic drug levels, undiagnosed cancer). Once these were managed, there were improved health status, sometimes including cognitive ability, improving the life situation. Studies demonstrate that co-morbid conditions are one of the major factors associated with increased costs of care for persons with dementia (Zhu, et al 2006). The results demonstrated that in the NCM counties, an increase number of persons with dementia in the community were identified. These elders and their family CGs had not previously accessed the current CM system or other community resources. Thus, the NCM intervention enabled more persons to receive dementia specific care and resources.

In the final 2 years of the grant a modified NCM position was tested to see if the model would be more sustainable and to expand numbers of clients served. This new model, the "memory loss nurse specialist" (MLNS) worked under the same conceptual framework as the NCM, initially involved in client care management to establish a plan of care and assist other case managers to continue coordination of services. The MLNS also worked more extensively in the community & in the CMPFE system as a resource, educator, advocate and consultant. The 2 MLNS from this grant are continuing in the second AoA grant and in modified roles after that grant ends in June 2007.

The NCM role, considered innovative and successful, was featured in the a regional conference sponsored by the AoA in Denver, CO in June of 2006.

## **SERVICES**

Types of services used by the clients were varied, but followed trends. The services **most used** by clients already in the CM system were **ones that were most available**;

- home delivered or congregate meals,
- home health care services, and
- homemaker services.

The **service types identified as needed** were in those same service areas. Services identified as needed were:

- social support and contact,
- transportation and
- professional services.

These services were **often not available in their area**, or if available, were not used by the clients. For example, even though support groups may have been available in the area and could have viewed as support for the CG, participation was small. Services the CMPFE program provided included increasing units of homemaker, personal care, professional services, respite and caregiver support throughout the grant period. Clients in the NCM counties were more likely to have more and increasingly diverse services than those in the traditional system. NCM training included linking interventions to identified CG needs so, it is likely that this was an attempt to fill the gap and meet those unmet needs identified upon enrollment. CMPFE members came to recognize the value of the NCM resource as evidenced by increased number of referrals, consultations, and requests for educational programming.

## **DIAGNOSIS**

There was a trend that only about a third (37%, n= 93) of the clients with memory problems had a *diagnosis* of cognitive impairment, with only 25% (n=64) who obtained the diagnosis by a specialist or specialty clinic. Most often the suspicion of or diagnosis was made by the family MD or while the disease was just suspected in 62% (n= 157). The lack of diagnosis of Alzheimer's disease or even suspicion of the disease in 67% of the care recipients pointed out the need for earlier and improved evaluation of persons with memory problems. The need for early diagnosis services as supported, not

only because progress of the disease may be delayed but to prevent the suffering of both the person with the disease and his/her CG. Future services need to address this problem.

### **COMMUNITY OUTCOMES/ AWARENESS**

In year three of the grant we added Nursing Outcomes Classification (NOC) community outcomes (Morehead, Johnson & Maas, 2003) to the evaluation portion of the grant. The two outcomes used for evaluation of community development were *Community Competence and Community Risk Control: Dementia*. The plan was to have these outcomes rated at the beginning of year 3 and at the end of year 4 by persons involved in the grant and other community participants. The definition of Community Competence is the ability of the community to collectively problem-solve to achieve goals. Community competence examines the percent of participation in planning, problem solving and communication among groups in the community. The definition of Community risk control is actions to reduce the risk of chronic diseases and related conditions. It assesses provision and participation of education, screening and services for persons with dementia.

In the 6 counties for which they were completed at baseline and follow-up, all but two counties had improvement in most of the indicators and overall improved to a higher level than at baseline. However, only one county improved to the level of good and none were rated excellent on the majority of indicators. This substantiates the assessment made generally about the success of the grant. Improvement was made in availability and use of services but there is a long way to go to have a seamless delivery system for persons with dementia and their families and community awareness of need for and availability of services.

### **LESSONS LEARNED**

- Under-diagnosis and under-treatment of dementia
- Physicians are not diagnosing or addressing issues of dementia; it is unknown whether this is due to unwillingness, stigma or lack of knowledge
- Too few geriatric centers in Iowa to provide thorough work up and diagnosis
- Lack of recognition of the fiscal impact NCM/MLNS involved in care of persons with dementia may have in delaying institutionalization and use of other resources (like ER use, hospitalizations, MD visits)

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- Lack of accessible affordable services- particularly assisted transportation, Adult Day Services & Respite service (identified through PLANS process), support groups for persons with dementia and caregiver training
- Lack of awareness that there are resource available to help manage persons with dementia
- Stigma of the disease and sense of isolation that persons with dementia and their CG feel
- Lack of awareness and knowledge about dementia on the part of the general public of effective interventions or available treatment
- Resistance to spending money on outside help- sense of pride and independent spirit of Iowans, especially rural Iowans
- Providers that lacked experience in or were uneducated about dementia
- Rurality- distances and limited services made access implausible especially with reimbursement
- Fiscal- many people fall through gaps because of being just over income levels, don't qualify for other programs, or were under minimum age (early onset dementia),
- Significantly more people living alone with dementia than national projections- which require special considerations
- Care for persons with dementia and their caregivers require a long term, comprehensive & complex system of care from a variety of professionals
- Families were dealing more than the issues surrounding dementia. They often had complex chronic health conditions, which were not being attended to
- As NCMs became recognized in the community, referrals were received from multiple sources (banks, grocery stores, pharmacies, judges, police, county assessors, utility companies, physicians, churches, social workers, and others). Numbers of referrals were more than anticipated and often unknown in the CM system. NCMs had difficulty keeping up with the new referrals received.
- The NCM position needs to be a designated position, not responsibilities tagged onto other roles; the case load and demands of another job limits the attention needed to provide this service. The NCM case load was in such demand as to justify a full FTE
- A limiting factor for nurses in this type of position is job security; nurses are not used to being on soft money and the agencies that contracted these nurses didn't have resources to guarantee salary & benefits.

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- Providers often didn't recognize clients had dementia, or have resources to bring in or send staff to expert training and education on dementia. They often based care and interventions not on evidence, but on tradition or "the way it's been done"
- Communities were motivated and capable of developing strategies to address needs of their community members with dementia, given education, opportunity and assistance

### **BARRIERS**

- Budgetary issues- on every level; services costly especially when issues of rurality are overlapping; failure to recognize long term versus short terms cost/ benefits
- There are institutional and personal biases and opinions of case managers- not wanting to "give services to people who weren't destitute"
- Opinion that this grant duplicated services- even though gaps of these services were evidenced in State gap analysis and it takes a variety of services presented in a variety of ways to begin to fill the needs
- Territorialism of agencies- feeling that one agency could and should provide all the education, and on another level in that case managers were reluctant to "share" clients, even though they didn't have the resources to meet the specialized needs of their dementia clients
- A limiting factor for nurses in an NCM position is job security; nurses are not used to being on unreliable grant money and the agencies that contracted these nurses didn't have resources to guarantee salary & benefits. They also don't typically recruit nurses so their experience doing so was unproductive
- Variable enforcement of DHS rules- cases of neglect, abuse and exploitation were reported and outcomes varied greatly by county
- Lack of support/ understanding of conceptual underpinnings of the interventions by some agency personnel

### **PROGRAMS INITIATED OR SUPPORT BY THE GRANT**

- Mobile respite in Cedar/ Iowa/ Monona counties
- DIALZ phone support programs (ongoing in East Central Iowa Chapter of the Alzheimer's Association)
- Support groups new ones in 6 locations (continuing)
- Adult day centers in Boone, Clinton

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- Memory Libraries in at least 4 communities
- Numerous educational series to community and professional groups (police, fire, MD offices, etc.)
- Wanderguard units (6) in 2 regions
- Multiple new community partnerships
- MLNS position to continue in 2 regions, one through financial support of community service groups
  - Training manual developed for training nurse dementia specialists
- Worked with Hospice to increase awareness of need for hospice services for persons with dementia and their caregivers: Early Hospice Referral Program
- Development of instrument for assessing safety for living alone (Assessment of Risk for Living Alone, ARLA); distributed to more than 120 sources, an instrument that could be used by multiple disciplines or family members (Instrument appended)
- Case management training
  - Developed and implemented series of training sessions for CM across the state
  - Worked with director of CM (IDEA personnel) to integrate dementia awareness into curriculum for CM
  - Worked on modifying CM enrollment to be more dementia specific

## **CONFERENCE: FROM JOY TO GRIEF: LIVING WITH DEMENTIA, APRIL 28-29, 2004**

- Professional conference on joy and grief in dementia care in conjunction with the National simulcast Living with Grief: Alzheimer's Disease from the Hospice Foundation
- 150 attendees from 6 states, 19 presenters from 5 states,
- Proceedings manual developed and provided to attendees
- Attendees from AD centers, ALs, NHs, colleges, private practices, home care agencies, students, researchers

**AoA Grant 2: “Enhancing capacity for dementia specific Adult Day Care and Respite for rural and emerging minority populations”, 2004-2007**

Participating agencies: the Iowa Department of Elder Affairs, University of Iowa College of Nursing, Heritage AAA, Siouxland AAA, Elder Services, Inc., Aging Services, Inc., Area XIV AAA, Alzheimer's Associations – Big Sioux Chapter, East Central Iowa Chapter, Greater Iowa Chapter

Adult day services and respite care were identified by participants in the PLANS process and service providers from the first AoA grant, as important components of and gaps in services for persons with dementia in the state. Therefore, this was chosen as a focus for the second AoA grant.

**STATE OF ADULT DAY SERVICES IN IOWA** (*summary report of Iowa AoA ADS survey, 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). Some 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.

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, diminished premature institutionalization, promotes caregiver wellbeing. The research on these benefits is variable, with research supporting both benefits and increased risk of institutionalization, though there are many identified problems with research done in this line of study; difficulty controlling for level of dementia and behavior issues, “dosage” issues of ADS services, services offered and training/ competence of staff at facilities, progression of disease, proclivity of CG for institutionalization to name a few. 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 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, additionally there is a lack of knowledge of their services and lack of connection of 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 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.

One of the first actions of the AoA grant was to survey all existing ADS and identified respite providers (per DIA 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 opinions about the new rules and regulations and how they might apply to their agency. (See report attached).

At the Annual 2006 Spring Conference of the 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 (10/13), 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 fit holds true. Part of the discussion focused as well on the barriers faced in sustaining their centers. The following are the challenges members identified in no particular order;

- 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

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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 before the crisis and need arises

Meeting state rules & regulations

Political environment- changing

How to manage client satisfaction

Staff competence and moral

Space, environmental design especially in sub-par conditions

Factors not listed in this discussion, but brought out in the day were about the background and preparation of ADS directors, which is that often the people directing ADS are not trained or educated in business management, accounting, marketing, or education. These are people who often "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 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.

## **OUTCOMES AND PROGRAMS**

- A series of ADS & R trainings were developed and evaluated
- 2 facility-based respite programs developed in rural communities
- One “drop-in” respite program developed in rural Iowa
- Continuation of MLNS in 7 counties
- A series of articles in the regional AAA newsletter on ADS resulting in increased inquiries and referrals to ADS & R
- Initiation of 5 support groups, one for persons with dementia, in counties where they didn't previously exist; by request, there is also 1 SG ready to start for persons with dementia and 1 for persons with atypical dementias
- New collaboration with the Mental health services agency
- Statewide committee (SWC) for evaluation of available training, producing a position paper (included)
- Convening of providers and regulating agencies through SWC into dialogue and collaboration
- Trial of N.E.S.T. training implementation and evaluation in ADS
- Approval for expanded provision of N.E.S.T. training across the state (4 conferences to be held in 2007) sponsored by the Adult & Gerontology Area of study, UI CON.
- Testing of observation and video taping as evaluation technique for training
- Survey of ADS about training needs
- Refinement of model for feasibility studies for ADS development; feasibility study done in one region
- Ongoing support, education and consultation for ADS by MLNS
- Development of outreach strategies to minority communities, and dementia materials translated into Spanish
- Clergy conference for dementia counseling/ support in one region
- Training of ADS staff in Spanish and Hispanic culture to enhance capacity for serving Hispanic clients
- Development of programs for caregivers in cooperation with Family Caregiver Specialist
- “Spa Day” intervention at ADS that provided student service-learning opportunities for health science students at University of Iowa

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- Incorporation of and increased awareness of the importance of the perspective of the person with dementia through sponsoring the events of Richard Taylor, person with dementia in the state (May 2007)
- Multiple educational sessions provided to service providers and facilities by the MLNS on dementia care
- Influence in setting the agenda for the Annual Long Term Care Conference (2007) to include the N.E.S.T. model
- Presentation to the Iowa Department of Inspections & Appeals surveyors and facilities on the N.E.S.T. approach and restraint free care
- Increase awareness of CM of needs of dementia clients resulting in increased referrals & services for persons with dementia
- Input into national research agendas on dementia through participation in Dementia Day Camp and development of the Consensus Report on Early Stage Dementia at the invitation of the National Alzheimer's Association

## **CONFERENCE: "AGING, DIVERSITY, AND DEMENTIA: INCREASING CULTURAL COMPETENCE IN THE AGING NETWORK", JUNE 3, 2005**

- Professional conference on cultural perspectives of dementia, developing culturally competent services, interpretation and translation, aging and culture
- 80 attendees representing a multidisciplinary audience-
- Proceedings manual developed and provided to attendees
- Attendees from AD centers, ALs, NHs, colleges, private practices, home care agencies, students, researchers, and case management

## **CONFERENCE: "N.E.S.T. APPROACH: A PROGRAM FOR ADULT DAY PROVIDERS", MAY 4-5, 2007**

- Despite the prevalent thinking that disturbing behaviors are the result of unmet needs or environmental stressors, this knowledge is not being used to design interventions. This training was created to provide a reliable approach to positive behavior change in dementia care

settings, based on the most current research evidence. Specifically, this is an evidence-based practice guide for disturbing behaviors of dementia for the geriatric care worker.

- Provided a statewide training for ADS staff, bringing in nationally known experts to teach the N.E.S.T. method, an evidenced based treatment of disturbing behaviors in dementia.
- This was attended by 50 people, with 26 of 34 licensed ADS represented in this 2 day training.

#### **LESSONS LEARNED REGARDING ADS & R INCLUDE**

- There are too few ADS through out the state and the number has declined
- Few existing ADS are 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 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.
- 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, they 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.
- 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.

## **BARRIERS**

- ADS main focus is in client care; they are not experts in business and marketing
- Educational opportunities are limited and expensive from the perspective of ADS & R
- Small staff at ADS makes attendance at educational offerings difficult to manage and keep the centers open
- ADS are not always familiar with rules and regulations and don't have the knowledge for compliance (administration of instruments like the Global Deterioration Scale)
- There is a lack of awareness by the general public about ADS services, and who should use them

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- There is no central listing of Respite service providers or formal training opportunities for respite providers
- Reimbursement for ADS for persons with dementia is inadequate and lower than for MRDD
- There was a recent cut in support from Veterans benefits for ADS & R services
- There is often a perception of the general public that they don't want their loved one with dementia in with those from other diagnostic groups (MR)
- There are no accommodation for differing stages of dementia (Orange County Model)
- There is a lack of support groups for individuals with dementia (with atypical dementias, early onset, or early stage)
- Often the infrastructure of rural communities that exists and would provide adequate and appropriate facilities for ADS & R services is limited & there are limited capitol resources available required to build a new facility. This makes establishment of new ADS & R not feasible for small rural communities.
- Agencies lack understanding of the need for and value of nurses in the care management of frail elder clients. This translates into inadequate salary packages, ineffective recruitment and retention, and unfilled nursing positions in rural community based settings.
- People in local organizations, service providers lack knowledge of grant availability and capacity in grant writing that may assist in obtaining financial resources needed to improve service options
- Often providers lack awareness of how to form collaborations and who to form them with, and how to implement them
- Resistance to change and innovation, and protection of the status quo
- Political and territorialism on all levels
- Perspective of providers that rules and regulations are meant to be punitive and that enforcement agencies surveyors often differ in their assessments and interpretation of rules and regulations, and enforcement.

## **OVERALL RECOMMENDATIONS**

Given the premises that:

- If persons with dementia and their caregivers are given support, adequate diagnosis and care management, they are able to be maintained in their home longer
- Well-being and stress of care givers can be address and mediated to some degree by adequate support and education
- There is a lack of awareness of and knowledge about dementia, the disease process and management of issues
- Many of the disturbing behavior issues connected with dementia are a result of inappropriate care or management of the manifestations of the disease
- Dementia care costs can be reduced by adequately providing services and support to care givers and clients with dementia by preventing premature institutionalization

## **RECOMMENDATIONS**

13. Promote education and training of professionals and paraprofessionals in geriatric mental health services, especially dementia care. This can be accomplished in several ways;
  - a. Ensure state supported education (community college & university) to be mandated to offer dementia specific courses in their curriculums, throughout the state at affordable costs, to all health care providers curricula
  - b. Offer certification programs to train respite providers & paraprofessionals to care for persons with dementia.
  - c. Encourage and fiscally support geriatric higher education initiatives in State institutions.
14. Improved reimbursement for dementia clients in ADS & R to be equitable to reimbursement for the mentally retarded/ developmentally disabled (MRDD) population rates and to include travel time for respite, which is especially critical in rural areas.
15. Foster programs that promote awareness of services available through PSAs and other means (for example, educate the public of the benefits of ADS & R care)
16. Sponsor programs/ technical support that foster development of community based/ driven initiatives for adult day programs, respite centers, "recreation clubs" for the elderly, support

services like friendly visitors, faith-based action plans, minority competence and service provision

17. Advocate for innovative demonstration initiatives in dementia care environments and work toward provisions in Iowa State code to allow for new models of care that are evidenced based.
18. Provide funding for and mandate integration of a "memory loss nurse specialist or dementia nurse care manager into each AAA to work in the CMPFE system to be a resource and referral source for formal and informal caregivers. Families dealing with dementia often are frail and elderly, experiencing multiple chronic illnesses. Because of this, nurses, when adequately trained in the specifics of dementia, can provide more holistic health care for and with the client and families to effect more positive outcomes than current case management.
19. Transportation, especially assisted transportation is urgently needed in rural areas provide access to services that do exist, and to support utilization of services that are developed. Financial assistance needs to be enough to not only pay for the services, but include the transportation needed to access the service.
20. Efforts need to address availability and quality of diagnostic services, focusing on early identification, is especially needed in rural areas.
21. There is a need to develop services that address the needs of persons with early onset as they often fall through the gap because of their age. They need access to appropriate diagnostic services, support groups for the person with the disease & CG, services focused on interventions for the person with the disease at their current cognitive level, and caregiver training.
22. Education for ADS & R needs to be provided to develop programs and capacity to serve diverse programs including brain injured, developmentally disabled, and persons with dementia, specifically on programming to integrate these populations. (Based on evidence presented by experts at the IADSA 2006 conference, sustainability depends on serving blended populations, not specifically targeted populations like dementia).
23. Involve individual community in designing and developing in dementia services for their areas (based on the PLANS model).
24. Review/ revise rules and regulations for dementia specific education and training to;
  - a. Ensure that dementia specific training is required in every level of service provision (EGH, AL, ADS, and NH).
  - b. Require specific content rather than number of hours of training

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- c. Is based in current evidenced based dementia care and recommended guidelines (see attached Maas & Buckwalter article)
- d. Build in positive incentives for facilities/ programs that exceed the minimal requirements (Illinois model).

## References

Algase, D., Beck, C., Kolanowski, A., Whall, Berent., Richards, & Beattie, (1999). Need-driven dementia-compromised behavior: An alternative view of disruptive behavior. *American Journal of Alzheimer's Disease and Other Dementias*, Nov/Dec 10-19.

Arnsberger, P., Fox, P., & Zhang, X (1999). Case Manager Defined Roles in the Medicare Alzheimer's Disease Demonstration: Relationship to Client and Caregiver Outcomes. *The Care Management Journals*. 1: 29-37.

Chen, A., Brown, R., Archibald, N., Aliotta, S., & Fox, P.D. (2000). *Best Practices in Coordinated Care*. Submitted to: Health Care Financing Administration Submitted by: Mathematica Policy Research, Inc. Division of Demonstration Programs. Contract No.: HCFA 500-95-0048 (04). MPR Reference No.: 8534-004.

Cohen-Mansfield, J., Jensen, B., (2007) Changes in Habits Related to Self-care in Dementia: The Nursing Home Versus Adult Day Care. *American Journal of Alzheimer's Disease and Other Dementias*. 22:3; 184-189.

Fitzsimmons, S., Buettner, L., (2002), Therapeutic recreation interventions for need-driven dementia-compromised behaviors in community-dwelling elders. *American Journal of Alzheimer's Disease and Other Dementias*. Vol 17(6) Nov-Dec 367-381.

Gwyther, L.P. (2001). The Nation Family Caregiver Support Program: From Enactment To Action. Highlights from the U..S. Administration on Aging Conference Held September 6-7, 2001 in Washington, D.C. Prepared by The Lewin Group. Care Management For Family Caregivers: An Overview.

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

Hepburn KW, Tornatore J, Center B, and Ostwald SW. (2001) Dementia Family Caregiver Training: Affecting Beliefs About Caregiving and Caregiver Outcomes. *Journal of the American Geriatrics Society*, 49(4), 450-457.

Hepburn KW, Lewis M, Sherman CW, and Tornatore J. (2003) The Savvy Caregiver Program: Developing and Testing a Transportable Dementia Family Caregiver Training Program. *Gerontologist* 43(6), 908-915.

Iowa Outcomes Project: Nursing Outcomes Classification (NOC), 3rd Edition. S. Moorehead, M. Johnson, & M. Maas, (Editors). St. Louis, Mosby, 2004.

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.

Kolanowski, A., (1999). An overview of the need-driven dementia-compromised behavior model. *Journal of Gerontological Nursing*, 25(9), 7-9.

McCann, J.J., Herbert, L., Yan Li, Wolinsky, F.D., Gilley, D.W., Aggarwal, N.T., Miller, J.M., & Evans, D.A. (2005) The effect of Adult Day Care Services on Time to Nursing Home Placement in Older Adults with Alzheimer's Disease. *Gerontologist*. 45:6; 754-763.

Naylor, M. Brooten, D., Campbell, R., Jacobsen, B., Mezey, M., Pauly, M. & Schwartz, J. (1999). Comprehensive Discharge Planning and Home Follow-Up of Hospitalized Elders: A Randomized Controlled Trial. *Journal of the American Medical Association*, 28: 613-620.

Noelker, L. S. (2003). Case Management for Caregivers. United States Department of Health and Human Services. Center for Communication and Consumer Services. Administration on Aging. <http://www.aoa.gov/naic/notes/carecasemanagement.html>. Retrieved 4/15/03.

Ostwald SK, Hepburn KW, Caron W, Burns T, and Mantell R. (1999) Reducing Caregiver Burden: A Randomized Psychoeducational Intervention for Caregivers of Persons with Dementia. *Gerontologist*, 39(3), 299-309.

Zhu, C.W., Scarmease, N., Torgan, R., Albert, M., Brandt, J., Blacker, D., Sano, M., & Stern, Y., (2006) Longitudinal study of effects of patient characteristics on direct cost in Alzheimer's Disease. *Nuerology*, 67:998-1005.

## **POSITION PAPER ON SERVICE NEEDS FOR PERSONS WITH DEMENTIA**

Developed by the Statewide Committee of the Iowa AoA; Alzheimer's Disease Demonstration Grant to the States (#90AZ2774)

### **Problem:**

Iowa is unprepared to meet the community based services needs of persons with dementia and their caregivers across the state.

### **Scope of the Problem:**

Currently 14.8% of the 2,962,324 Iowans are over the ages of 65, with 65,118 or (2.2%) persons over the age of 85. Prevalence rates are 7% for the age 65-74, 53% age 75-84, 40% age 85 and up. Incidence of the disease doubles every 5 years after age 65 until after 85-90. This consistently demonstrates an exponential growth as a function of age. By 2030 the U.S. Census Bureau projects the number of persons over the age of 85 in Iowa to be 119,817, which brings the estimated number of people with AD/DR to be 43,621. Since the 85 plus age group is the largest growing segment of the population in Iowa, we need to prepare to serve many more persons with dementia. (Source; US Census data, 2000; Morris 2005 & 2006).

There is already evidence of a need for increased service.

- Limited number of persons with dementia in adult day services (ADS); 34% of person receiving ADS have dementia (IA AoA survey, 2006) compared with national figures which reflect 50% of persons served in ADS have dementia.
- ADS & R (respite) are consistently identified as some of the most needed and unavailable services across the state (DEA Needs Survey 2002, NCM reports 2003 AoA grant)
- Lack of transportation limits many from receiving ADS services because the cost of transportation uses up the funds available for ADS
- Decrease in number of ADS providers from 88 to 38 currently (DIA, 2007) which is in part due to the re-defined attributes of an "adult day service" provider versus a "day rehabilitation center".

There is lack of recognition of the problem in planning programs and services

- Only 30 % of persons who are identified with memory problems actually have thorough diagnostic evaluation to determine the presence of Alzheimer's or other dementias (AoA grant, 2000)
- Lack of recognition by and of persons with dementia served by case management (AoA grant, 2000).
- No requirements as to education or training of CM in new DHS CM rules
- Life long Links did not include specific information for persons with dementia or their families.

There is a lack of training in dementia for care providers.

- Little to no dementia training for case managers and little assessment data to help identify the problem in clients & only recently dementia was added to the accepted suggested topics for continuing education for CM
- There are only 6 hours of required dementia training for dementia-specific assisted living (even though we know there is a high rate of dementia in regular assisted livings) & ADS
- There is little formal educational content on dementia in health professional curriculums
- AoA ADS survey identify there is a need for additional training related to AD
- ADS providers report barriers to training as cost, availability, and limited options other than the same 6 hour material. (IADSA meeting Fall 2006).

**Solutions:**

Based on this information we have 4 recommendations:

- A. Ensure state supported education be mandated to offer dementia specific courses in their curriculums, throughout the state & at affordable rates, to all health care providers, and to offer a certification program to train respite providers to care for person with dementia.
- B. Provide funding for & mandate integration of Memory Loss Nurse Specialists into each AAA to work in the CM system.
- C. Increase reimbursement for ADS & R to be equitable to reimbursement for the Mentally Retarded/ Developmentally Disabled (MRDD) population rates and to include travel time for respite, which is especially critical in rural areas.
- D. Review rules and regulations for dementia specific education and training
  1. Ensure that dementia specific training is required in every level of service provision (EGH, AL, ADS, and NH).
  2. Require specific content rather than number of hours of training.
  3. Build in positive incentives for facilities/programs that exceed the minimal requirements (Illinois model).

**SIGNS TO WATCH FOR IN PEOPLE WHO LIVE ALONE OR  
WHO ARE AT HIGH RISK**

The following factors may indicate when a person with dementia is no longer appropriate to live alone or at minimum requires greater services are needed.

**Classification:**

**A = Emergent** – Immediate help/placement required. Only one factor needs to be present

**B = Semi-Emergent** - Not an immediate threat to safety or well-being. May wait a few weeks, but there is a clear need for in-home services or support or work towards placement. Increasing safety risk when two or more are present

**C = Non-Emergent** – Consider additional help, especially when three or more are present. Re-evaluate monthly  
Combined letters indicate the ranking depends on reviewers perception of severity

Reported or observed conditions

**A. Grade**

**B. Observed conditions**

- A
- Weight loss of > 6 lbs or 10% body weight in 6 months; loose clothing, evidence of wasting (protruding bones)
  - Florid (agitated) paranoia, hallucinations, delusions, suicidal thoughts, aggression
  - Weapons present, especially loaded
  - Evidence of misuse of appliances or equipment, evidence of fire
  - No food in house or rancid food
  - Falls (especially with long lie >2 hrs), evidence of injuries, unexplained bruises, evidence of substance use
  - Medication mistakes or poor care for potentially life-threatening/unstable conditions
  - Reports of self-neglect or dependent adult abuse, founded or unfounded
  - Repeated ER visits, hospitalizations, physical complaints
  - Evidence of caregiver injury, domestic violence
  - Calls police or emergency services frequently
  - Wandering outside the home
  - Eviction notice served
- A/B
- Malfunctioning plumbing, especially no water or toilet stoppage
  - Thermostat set inappropriately for weather conditions
  - Chronic anxiety, panic attacks, chronic worry, depression
  - Unsafe driving, refuses to stop
  - Law Enforcement referred
- B
- Poorly managed incontinence
  - Repeated calls to family or others asking what to do next or expressing concern about planned activities
  - Dirty or infested household that poses risk to health
  - Garbage accumulation
  - Food stored inappropriately (Ice cream in closet)
  - Exploitation by neighbors, friends, relatives, others
  - Resists personal care for prolonged periods of time
- B/C
- Client states "I need to move," "I can't take this much more," or otherwise indicates he/she feels a move is imminent
  - Neighbors and others complain of unwanted or unrealistic dependence on them
  - Phone calls from community members advising help is needed
- C
- Vegetative or socially isolated behavior (sitting all day with TV on or off)
  - Missing belongings, hiding things
  - Poor grooming and wearing same clothing all the time, clothing is soiled
  - Post-it notes throughout house

# Enhancing Capacity for Dementia in Adult Day Care and Respite for Rural & Emerging Minority Populations in Iowa

Report of the Adult Day and Respite Survey  
January 2005

AoA Rural Iowa Alzheimer's  
Demonstration Project  
#90AZ2774

By Ann Bossen, University of Iowa Project Coordinator

Report of ADS & R Survey May 2005

In Iowa the environment of Adult Day & Respite services 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. Nation-wide there is a shift in elder care toward Home and Community Based Services, Adult Day and Respite (ADS &R) being one of those services. The numbers of ADS & R providers in the state is diminishing from an earlier report of 83 providers of ADS to a recent list obtained from the Department of Inspections and Appeals listing 34 providers with a capacity of 534. Some would argue that there already existed a gap in this type of service available especially for those in rural areas. ADS & R services are one way demonstrated to reduce the caregiver burden and stress of caring for people with dementing illnesses (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.

The purpose of the rules and regulations is to improve the quality of care provided by ADS. This may create a difficult environment for some ADS to meet for a variety of reasons. Some agencies provide ADS & R services as an adjunct to their main services, for example, as a nursing home or assisted living agency. It may be because of limited resources; size of agency, cost effectiveness for number of clients served, geographic location (ruralness) etc. Inability to meet standards causes some agencies to close because of poor quality, so the concern of the grant is that there be accessible appropriate services. This may mean some agencies need extra help to understand and meet the standards. One of the roles of this project is to help augment resources so that not only will quality be improved but that capacity can be increased.

The purpose of this survey was to begin to develop a base of knowledge of the current dementia specific education and training for direct care and administrative Adult Day and Respite services in the state of Iowa. The survey was done in an effort to look at how direct services (DS) workers/ providers as well as their administrators felt about the training they receive, what areas they found not to be adequate, areas of interest, and how often and adequate they perceive current training to be, especially in light of current policy changes..

Capacity building is a process, and as with any process, knowledge of the current status is an important beginning point. It is essential to know where an agency is in the process of dementia & care management and importantly what the staff perception is. If they are not satisfied with their level of training and support (knowledge, skills, or using Bandura's concept of self- efficacy), their capacity is limited to care for clients at a higher (more functionally impaired) level of dementia.

Agencies often report behavior issues as highly associated with a client no longer being able to attend the center. Long term care placements are often related to client behavior. Adequately trained staff is able to create an appropriate environment, to minimize catastrophic reactions, and know their clients and appropriate responses to deal with their clients in moments of stress where catastrophic reactions (behavior outbursts) are apt to occur. Assessing the status of training and where the educational needs fall short is integral in determining a strategy for developing a more comprehensive training (building capacity).

Research links empowerment of direct service (DS) workers to education and training in the Long term care (LTC) environment. Empowerment has been linked with retention, job satisfaction, and therefore is a component in quality of care. From this survey we hope to develop a better understanding of how to empower DS providers and build their capacity to serve higher levels of clients with dementia.

## Iowa's Area Agencies on Aging



Geographic distribution of agencies responding (58 counties), divided by governmental organization of Area Agency Units.

## Survey Results

### Demographics of who responded

Who were these mailed to?

- Batch one included those agencies currently certified or have applied for certification from the Iowa Department of Inspections & Appeals (IDIA).
- Batch two included agencies identified by a county search through Caregiver's website for ADS.
- Batch three included agencies identified by a county search through Caregiver's website for Respite Providers.

**Table 1. Response Rate**

	Sent	Responses	%
<b>Batch 1 (DIA list)</b>	34	28	82%
<b>Batch 2 (ADS)</b>	65	22	34%
<b>Batch 3 (Respite)</b>	61	19	31%
<b>Total</b>	160	69	43%

### How many agencies:

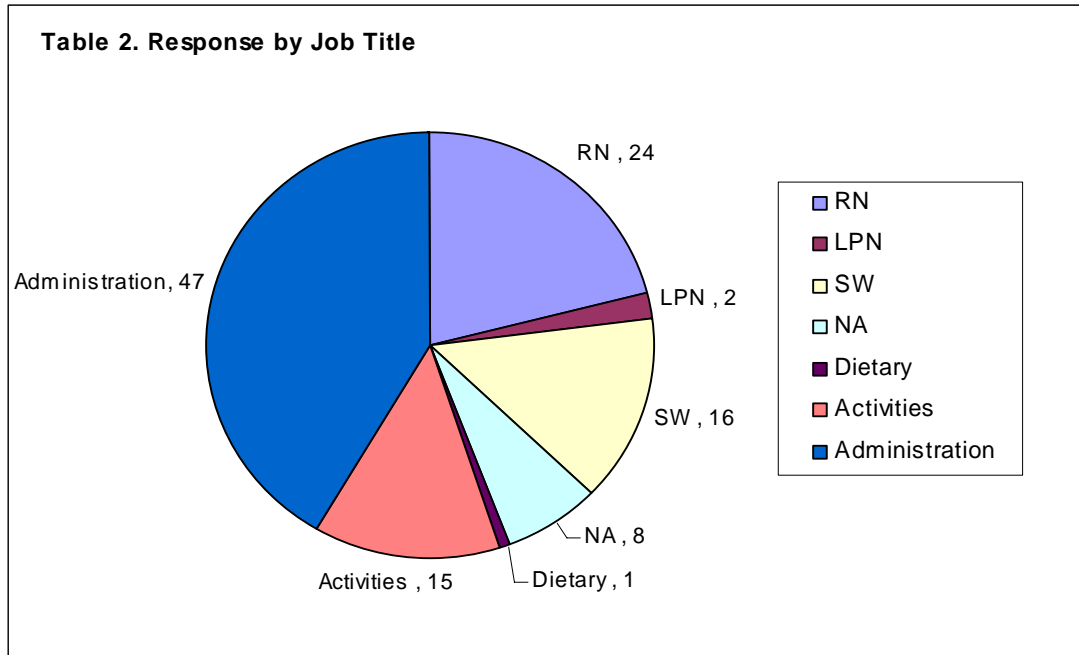
Agencies were asked to have multiple people & job titles fill in the survey as we were interested in a range of perspectives.

Agencies responded	n = 69
Total number of forms	n = 108
Counties were represented	n = 42 (out of 99)
Number returned out of operation	n = 7

### Job Title:

RN/LPN	n = 26
SW	n = 16
Administrator	n = 47
NA	n = 8
Dietary	n = 1
Activities person	n = <u>15</u>
Total	113

\*some indicated 2 positions



**How many staff does your agency have?**

**FT**            **Range** 1-65  
**PT**            **Range** 1-45  
**Volunteer**   **Range** 1-150   **Average**      14.9

\* This number is being reported as a range since agency size thus staff size varies tremendously.

**How many clients does your agency currently serve?**

**Per week**      **Range** 1 to 100      **Average**      21.6      **Total** 909  
 \*of 44 agencies responding  
**Per month**    **Range** 1 to 735      **Average**      80      **Total** 2962  
 \* of 40 agencies reporting

This number is being reported in a range, average & total since agency size thus client capacity varies tremendously.

**How many dementia clients does your agency currently serve?**

**Range** 1 to 135      **Average**      14.9      **Total** *n* = 672  
 \* of 48 agencies reporting

**Method of training currently used:**

Staff learning modules	<i>n</i> = 27	25%
Send to courses	48	44%
Internal Staff training	87	81%
Bring in speakers	57	53%
Workshop/conferences	73	68%
Other	11	10%

\*Total >100% as may list more than one

## AoA Rural Iowa Alzheimer's Demonstration Project 2005

### Others listed included:

Computer based training, videos, movies, trips, staff meetings, safety meetings, periodicals, Memory Loss nurse specialist, manuals, staff to staff, franchise materials, local nursing homes join staff,

### Frequency:

Whenever we need it	45	42%
Every semester	2	2%
The frequency required too meet state regulations	21	19%
Not often enough	18	17%
When there is a problem	13	12%
Upon request	12	11%
once a month	48	44%
Other	14	13%

\*Total >100% as may list more than one

### Others listed included:

Yearly, as often as able, weekly internal, quarterly, ongoing, every 2 weeks, 2-3 times a year.

### Who provides:

Alzheimer's Chapter	37	34%
Individuals	88	82%
Community College	33	31%
Other	15	14%

### Others listed included:

College students doing practicum, community professionals (physical therapists, co-workers, physicians, pharmacists), Mental Health experts, Public Health nurses, geriatric specialists, professional seminars.

### Characteristics they feel suite the needs in training:

Low / no cost	67	63%
Group sessions	53	50%
Combination of types (lecture & interactive)	55	52%
Available on site	51	48%
Video series	45	42%
Combination of activities	42	40%
Interactive sessions	40	38%
Offering must be within 20 mile radius	29	27%
Limited time sessions	25	24%
Self learning modules, computer based	23	22%
Different sessions for CNA , Nurses, Administrators	20	19%
Offering must be in community or	19	18%
Self learning modules, written	19	18%
Lecture type sessions	12	11%
All day sessions	9	8%
Others	0	0%

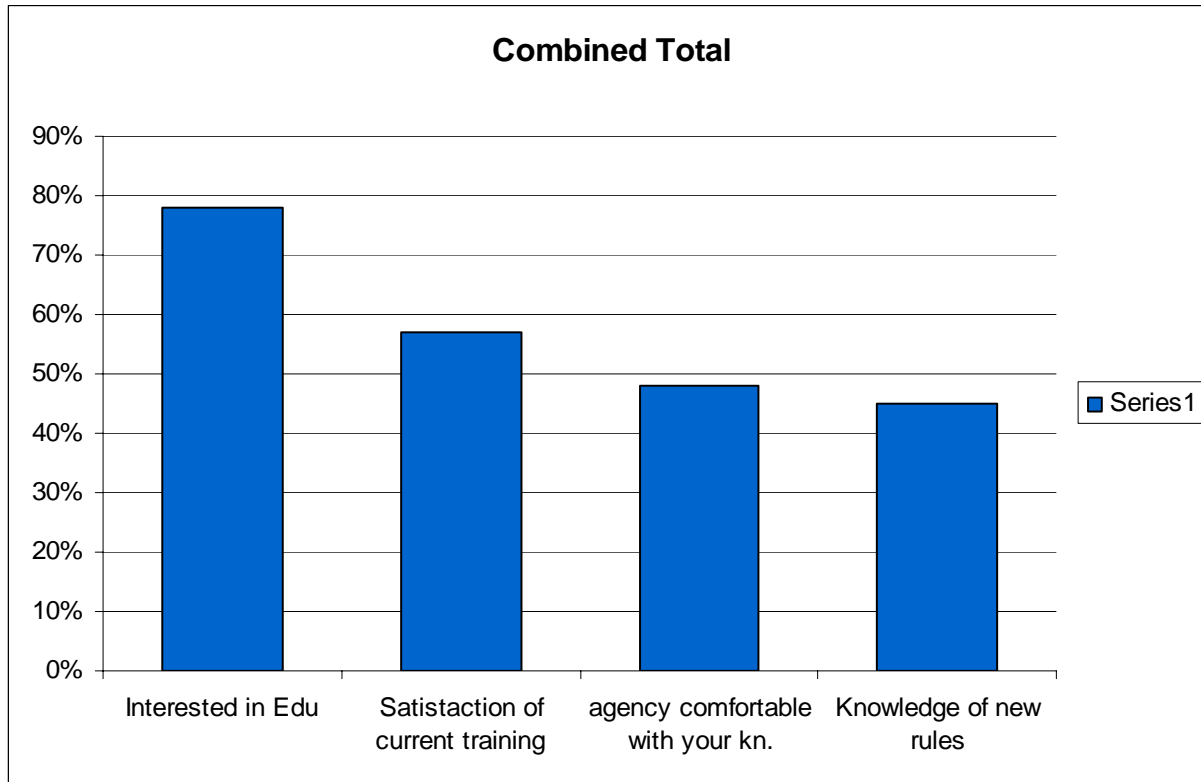
**Topics of Interest/ need in trainings:**

Topics:	Number	Per cent
Activities and dementia	67	63%
Behavior Management	63	59%
Disruptive Behaviors	63	59%
Communication	52	49%
Fall prevention & physical activities	44	42%
More on the Disease process & expectations	34	32%
Dementia training for Developmentally Disabled, Mentally Retarded.	29	27%
Person Centered care	26	25%
Family involvement	25	24%
Learning in persons with dementia	25	24%
Alternative Therapies	24	23%
Nutrition/hydration	24	23%
Understanding Pain in dementia	22	21%
family education	21	20%
Medication management	21	20%
Physical environment	21	20%
Dining and eating issues	20	19%
Grief & loss	17	16%
Incontinence	16	15%
GDS applied to care	14	13%
Training for support group leaders	10	9%
Bathing Techniques	8	8%
Other	1	1%

Others listed included: Weight reduction

The final four questions are put into graph form for easier visualization.

- 1. Would your agency be interested in using education that would also assist you to meet certification criteria?**
- 2. Do you feel your current training meets your needs?**
- 3. Is your agency comfortable with your knowledge of & how to implement the new Iowa Rules and Regulations as they pertain to ADS?**
- 4. Do you know how new State rules and regulations will apply to you and your facility?**



This chart represents the YES answers to the posed questions for all of the agencies combined. Table 3. Breaks down the responses to these four questions by batch groups, DIA, ADS web list and respite list. This was done as these agencies are often very different in composition, administration, size, purpose and current state of knowledge and interest.

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**Table 3. Training, Rules & Regulations**

	DIA list					ADS weblist					Respite					Combined				
	Yes	No	NA	Total	Job title*	Yes	No	NA	Total	Job title*	Yes	No	NA	Total	Job title*	Yes	No	NA	Total	Job title*
Would your agency be interested in using education that would also assist you to meet certification criteria?	50 (86%)	4 (7)	4 (7)	58	2RN, 1SW, 1A	19 (79)	3 (13)	2 (8)	24	1NA, 1SW, 1A	14 (56)	2 (8)	9 (36)	25	1RN, 1A	84 (78)	9 (8)	15 (14)	108	3RN, 2SW, 1NA, 3A
Do you feel your current training meets your needs?	37 (64)	11 (19)	10 (17)	58	2N, 1SW, 1NA, 6A, 1AT	16 (67)	6 (25)	2 (8)	24	4N, 1SW, 2A	9 (36)	9 (36)	7 (28)	25	1N, 3SW, 6A	62 (57)	27 (25)	19 (18)	108	6N, 5SW, 1NA, 1AT, 5A
Is your agency comfortable with your knowledge of & how to implement the new Iowa Rules and Regulations as they pertain to ADS?	40 (69)	9 (16)	9 (16)	58	8RN, 5SW, 1NA, 3AT, 9A	10 (42)	9 (38)	5 (21)	24	4RN, 1SW, 1AT, 1A	2 (8)	6 (24)	17 (68)	25	2RN, 2SW, 2A	52 (48)	25 (23)	31 (29)	108	8RN, 5SW, 1N, 1A, 3AT, 9A
Do you know how new State rules and regulations will apply to you and your facility?	38 (66)	13 (22)	7 (12)	58	1RN, 1SW, 2NA, 6AT, 3A	8 (33)	12 (59)	4 (17)	24	3RN, 2SW, 1NA, 1AT, 1A	3 (12)	15 (60)	7 (28)	25	6RN, 2SW, 1NA, 5A	49 (45)	41 (38)	18 (17)	108	11RN, 5SW, 4NA, 7AT, 14A

\* The job title break down is related to those answering NO to the question. N or RN = nursing staff; SW= Social workers; A= Administrators and assistant administrators; AT= Activities people; NA= nurse aides or universal care workers.

The next two sections were in narrative format. For ease in analyzing they were sub-classified to count.

### **Barriers & concerns:**

Comments listed as barriers or concerns identified several themes so they were divided and counted in aggregated areas. Responses were broken down into categories of responses with 6 main themes determined; *Time* (related to training time, coverage issues, travel issues), *Cost*, *Quality/content*, *Practical issues* (distance, format, availability), *Staff openness* (attendance, acceptance) and *Access* (not available). There were a total of 95 different comments. The following refers to the number of times that item was identified as a barrier or issues pertaining to training. It will not add up to 95 as the category "other" makes up the remaining.

▪ Time	32
▪ Cost	18
▪ Quality/content	10
▪ Practical	9
▪ Openness of staff	8
▪ Access	7

There were several responses that didn't fit into categories. They were listed as "Other" and are as follows;

- nursing department needs supervisory training;
- need training for volunteers;
- not enough dementia clients to make it worthwhile;
- rules and regulations;
- staying current with new staff;
- awareness of what's available;
- don't understand what is needed;
- like to train staff together;
- would like professional staff trained to be able to do training;
- and simply "need more".

### **Additional comments of interest:**

There were an additional 39 comments listed at the bottom of the survey. These are listed with duplicates removed. They are as follows:

- the agency only provides mainly caregiver relief for a few hours a week;
- would be nice to have variety of speakers on different topics r/t dementia;
- activities therapy course needs to broaden scope of education on dementia;
- need to include different environments;
- changed to day hab service;
- feels their corporation provides good training, don't need more;
- looking at doing an ADS program but don't have currently;
- currently have own training but would like supplementation;
- just been alerted to need for training;
- need to learn about rules & regs changes in timely manner;
- need more for applying knowledge from trainings;
- need new material for CCDI course- there is too much repetition;

- need more info on medications;
- need more from experts on disease process & treatments;
- trainings need to be offered in closer proximity to work/ living sites;
- limited resources in rural areas; tailor training to different environments (size, type);
- cost of certification not worth the hassle;
- ceasing offering ADS because of burdens from DIA (already meeting criteria as NH, additional for ADS & R overwhelming for demand);
- changes in new rules not conveyed well to providers.
- better communication from the state would enable us to provide services up to DIA expectations;
- need a workshop just on new state rules.

## Highlights

Almost 80% were interested in additional training geared to dementia and the rules and regulations. Only about 50 % of those responding felt their training was adequate.

Less than 50 % of those responding felt they understood the new rules and how to implement them. This included 28 that have applied for or received certification from the State.

7 surveys were returned with an indication that they were no longer serving clients.

The range in size of agencies is from 4 clients per day to 50.

The number of dementia clients being provided service is proportionately to projected numbers of persons with dementia and total clients being served is very low.

## Implications

Part of the new rules and regulations rely heavily on the use of Reisberg's Global Deterioration Scale (GDS) in determining client status, staff ratios & "appropriateness" of staff issues in the ADS environment. Clearly with only 4 people, or less than 1% indicating interest in the GDS, and less than 50% reporting an understanding of the new rules and regulations, the GDS is one area where training is indicated. The current level of dementia of clients in ADS & R is typically not very impaired, perhaps a GDS of 3 to low 4 on the GDS. Anecdotally, incidents of mis-handling of clients non-Alzheimer's type or later stages of dementia contribute to behavior problems in the ADS environment. This points to the concern that care is inappropriate due to lack of knowledge and understanding of how different types and later stages of dementia leads to misunderstanding client needs.

Also identified in the survey that is critically important is the level of knowledge and comfort with rules and regulations by the agencies. One particularly interesting comment addresses the lack of knowledge and communication of changes in rules and regulations. If the goal is to increase capacity of the ADS environment then knowledge development and communication of these issues are of critical. Collaboration with state agencies responsible for the development, oversight and regulation of the rules is of obvious importance and could be one strategy useful to that end. Another strategy may be in the development of an electronic list serv for support and communication between ADS and governmental agencies.

Of a total of close to 1500 clients served monthly only approximately 430 identified as having dementia (29%). National statistics indicate that the percent of dementia clients in ADS on average is greater than 50%. Reasons for the lower percentage of dementia clients served in Iowa ADS may include lack of recognition/identification of the need; inability to care for ADRD clients; the traditional

underuse of ADS by persons with dementia (which now seems to be changing) and the lack of recognition of the need for ADS services for specific populations (MRDD) or ethnic groups. Even though a large number of counties have an ADS & R provider, there are large geographic gaps in this type of services. Breakdown of clients served by ethnicity was not done, but reportedly and from previous data from the AoA grant, there are very few minority clients being served.

Many of the agencies identified using internal methods and staff as a source of training. Comments indicated there is some need for developing those training and supervisory skills in ADS staff. Developing or identifying a training module to assist ADS provider staff in effective training and supervisory roles may be one strategy useful in enhancing capacity through training. This would address the prevalent issues of cost and time as well as access.

One area not covered by the survey is the level of technology available and computer knowledge/comfort of employees. Trainings on dementia are available as computer based self learning modules. Evaluating the access to and knowledge of computer for implementation of training may be another strategy to pursue.

This survey has identified gaps in ADS & R services in access, availability, and capacity. The findings point to a select small group of providers that are confident of providing quality of care, but also interest in the larger environment of ADS & R provision in Iowa. Indications point to belief in the adage that what makes a service good is always realizing that there is room for improvement and always striving for that higher level.