

**Alzheimer's Disease Demonstration Grants To States**

**The Usefulness of a Consumer Directed  
Voucher Program for Caregivers**

**State of Nebraska**

**Executive Summary**

**2003-2006 Funding Period**

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**ADDGS – Alzheimer’s Disease Demonstration Grants to States – Nebraska  
Data Collection Period: November 2003 – June 2006**

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There are several people who have been involved in this demonstration project since its inception. Their perspective on caregiving and the effects of Alzheimer’s disease has served to shape the program and its offerings. The members include:

**Steering Committee Members:**

Scott Adams, Director, Catholic Charities  
Mary Ann Borgeson, Governing Board, Eastern Nebraska Office on Aging (ENOA)  
Edsel Buchanan, Midlands Chapter of the Alzheimer’s Association  
Betty Foster, Midlands Chapter of the Alzheimer’s Association  
Beverly Griffith, Director, Eastern Nebraska Office on Aging (ENOA)  
Duane Gross, Director, Midlands Chapter of the Alzheimer’s Association  
Paul Maginn, Franciscan Adult Day Program – New Cassel  
Michaela Myers, Care Consultants for the Aging  
Lana Pleak, Memorial County Hospital and Health System  
Chuck Powell, University of Nebraska at Omaha – Department of Gerontology  
Paul Thomsen, Caregiver  
Joann Weis, Director, Nebraska State Unit on Aging  
(note: members of the work group also attended the steering committee meetings)

**Work Group Members:**

Janice Price, Project Director, Nebraska State Unit on Aging  
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Hester Montgomery, Eastern Nebraska Office on Aging (ENOA)  
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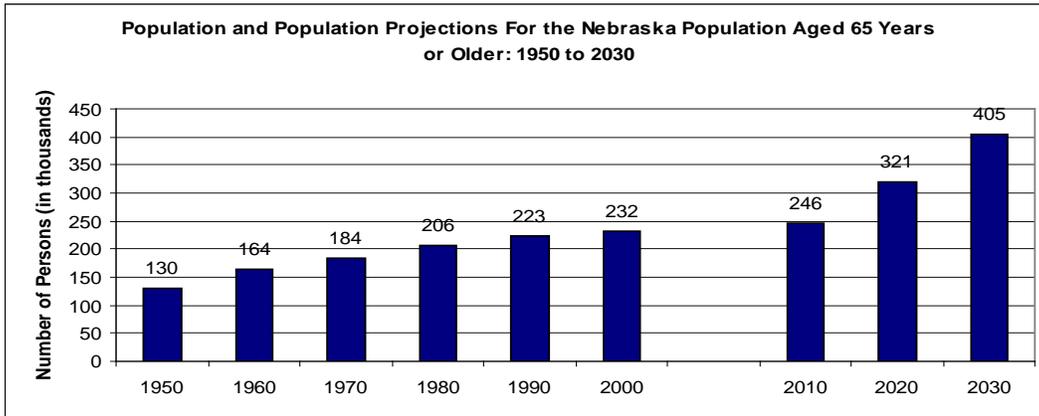
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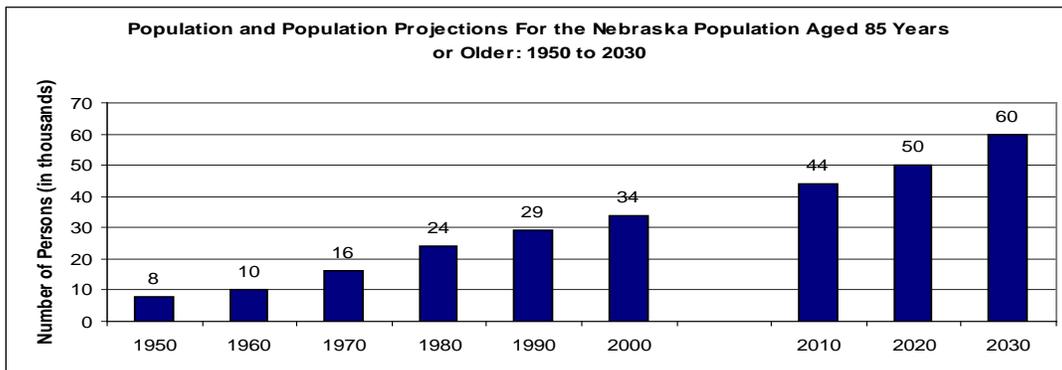
Note: A copy of the full report may be obtained by contacting Julie Masters at [jmasters@mail.unomaha.edu](mailto:jmasters@mail.unomaha.edu)

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The aging of the population in general, coupled with the number of persons who currently have or are projected to be diagnosed with Alzheimer’s disease (especially those 85 and older), suggests a potential caregiving crisis in this country. Because families provide the majority of care to persons with Alzheimer’s disease, finding ways to support and encourage them in this role is needed now more than ever. The graphs below highlight the growing need for care.



Source: 1950 to 2000, US Census Bureau, Censuses of Population and Housing 2010 to 2030, Projections prepared by Center for Public Affairs Research, University of Nebraska at Omaha.



Source: 1950 to 2000, US Census Bureau, Censuses of Population and Housing 2010 to 2030, Projections prepared by Center for Public Affairs Research, University of Nebraska at Omaha.

Source: Prevalence calculations by the authors using 2000 US Census Bureau, Censuses of Population and Housing 2010 to 2030, Projections prepared by Center for Public Affairs Research, University of Nebraska at Omaha.

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## **Reasons Caregivers Favor a Voucher Program**

There are many reasons why caregivers provide care to a family member with Alzheimer’s disease and why a voucher program can support them in this role. The 109 caregivers who participated in this Administration on Aging (AoA) demonstration grant provided several thoughtful comments as to why the voucher allowed them to keep their family member at home. Some of the more telling remarks include:

*“I hope they continue the program. It was good. I had to take early retirement so I could care for my wife. The vouchers helped a great deal. “*

*“If you keep people at home it works better. I appreciate the grant and what it did for me and my mom. My thanks to ENOA for coming to my office to work with me – they do so much for helping people. It’s been a gift to have her.”*

*“The voucher system was good because I had a choice. For me it was a very positive experience and the support staff at ENOA. Financial aspect was great. Could use the funds as I needed them. Would like to have the program continue.”*

*“A marvelous growth experience. I hope that more can be done to broaden the availability of the grant to keep people in their homes and avoid nursing home placement.”*

*“I don’t know how people will do without it. I am not certain people can manage. I wrote the Governor and Senator Nelson about the program. The voucher was very helpful - especially knowing someone could help my wife if I could not.”*

## **Introduction and Background**

In 2000, and again in 2003, the Nebraska State Unit on Aging (NSUA) in partnership with the Eastern Nebraska Office on Aging (ENOA) and the Midlands Chapter of the Alzheimer’s Association received funds from the Administration on Aging (AoA) to explore the benefits of a voucher program for caregivers supporting a family member with Alzheimer’s disease. The findings from this grant suggested those caregivers who had the freedom to select their own services, generally more non-traditional in nature, were more satisfied and more likely to continue in their caregiving role than those receiving traditional aging services such as adult day care or in-home services.

A second grant was funded by AoA for the 2003 – 2006 funding period to continue to explore the benefits of vouchers for caregivers using a consumer directed model as well as examine the usefulness of mental health support and regular contact by a volunteer trained in addressing caregiver issues. The highlights of this grant follow.

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## **Project Highlights**

### **Care Receiver and Caregiver Characteristics.**

- A little over half of the care recipients 54.1%, were female.
- The average age of care recipients was 82.65 years, with an age range of 67 -102 years of age.
- While the majority of caregivers were female, (60.6%), almost 4 in 10 caregivers were male.
- Caregivers were younger with 50 % under the age of 65. The average age was 66.59 years, with a range of 32 – 92 years of age.
- 70 % of care recipients had an income less than \$20,000 per year while 47 % of caregivers reported an annual income less than \$20,000. To put in a different perspective, the \$300 monthly voucher would represent 20% of a \$20,000 income.
- 40 % of caregivers were fully retired while 27 % continued to work full-time.
- 41.9 % of caregivers had provided support for their family member for at least 5 years while 37.2 % had been providing care for at least 2 years.
- Overall health ratings of caregivers improved between intake and the exit survey, although this improvement was not statistically significant.
- Scores on the Center for Epidemiological Studies Depression Scale (CES-D) at intake suggested 4 in 10 caregivers were depressed. Yet, only 7 % of caregivers participated in any mental health counseling as a benefit of the grant.
- At intake, when thinking about the daily challenges faced by care receivers the caregivers in this study identified several Instrumental Activities of Daily Living (IADLs) which required assistance. Those identified as requiring “a lot of help” included going places outside of walking distance, managing money, cooking/preparing meals, laundry, buying/getting food and clothing and light to heavy housework.
- Services found to be most helpful to caregivers in their responsibilities included care management (74.4%), adult day care (41.9%) and, companion or friendly visitor (40.7%). Caregivers also identified paid supervision (36%) and homemaker services (33.7 %) as being most helpful to them. Service use increased between intake and the exit survey – especially with adult day care and respite.
- Caregivers in this study found the educational materials provided at intake and then throughout the duration of the program to be useful. Materials found to be of value were quick and easy to read – especially for persons whose time was consumed with caregiving responsibilities.

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## **Program Summary**

The major finding from this demonstration grant is the perceived benefit of vouchers for caregivers. Regardless of their financial need, caregivers found the monthly voucher to be of great help to them in their caregiving role. For those whose incomes were limited because of the expense of medications and/or purchasing in-home services, the grant offered support for such essential items as groceries and offsetting the cost of medications. The consumer directed nature of this grant gave caregivers the flexibility to choose which goods or services they felt would help them in keeping a family member at home.

Another finding of interest was the availability and use of alternative services to nursing home care. Based on voucher receipts for the three year period, caregivers used their vouchers to purchase services such as adult day care, respite and homemaker services. They also used their funds to purchase groceries, buying prescriptions or over-the-counter medications. Moreover, for those who were initially reluctant to spend their own personal funds on adult day services or in-home respite, the grant allowed them the comfort and security in trying out other options without impacting their monthly budget. Additionally, the use of creative options such as a gift certificate and allowing companions to accompany care recipients to sporting events (e.g., hockey and golf) provided caregivers with unique non-traditional opportunities for respite while at the same time giving care recipients opportunities for enjoyment.

As will be discussed later in this report, very few caregivers took advantage of the mental health services made available to them. Even though funds were available to cover this expense, only 6 of the 109 caregivers took advantage of this benefit. While on the surface this was somewhat disappointing, the minimal usage is not out of the ordinary when compared with older adults in the community.

Finally, an on-going theme with this grant and the previous AoA funded demonstration grant continues to be the value of having a support system for caregivers. While circumstances surrounding personnel may not always allow for consistent and reliable contact to occur, attention should be given to meeting this goal. Caregivers from both grants remarked how helpful it was to have someone to call when things were unclear or during those times when the caregiving role proved to be overwhelming. Whether they called ENOA or the Midland’s Chapter of the Alzheimer’s Association, it was a relief to the caregiver to have someone to go to for assistance or just listen.

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## **Overall Design**

Care receivers and caregivers were recruited from the initial AoA funded grant and from traditional referral sources such as adult day care, geriatric assessment centers, support groups, ENOA and the Midlands Chapter of the Alzheimer’s Association.

At the beginning of the grant, caregivers received \$300 each month to use as they saw fit with the expectation that 50% of the funds would be used for traditional direct services (i.e., respite, adult day care, and in-home support). All other dollars could be used for such non-traditional items as incontinence products, groceries and medications. Six months before the conclusion of the grant, the monthly amount allotted to caregivers was reduced to \$200 to ensure there was sufficient funding for the remaining months.

Additionally, a mental health component and support from a volunteer program (First Contact Volunteers) managed by the Midland’s Chapter of the Alzheimer’s Association was included. Funds from the demonstration grant were available to pay for mental health services from one of three mental health providers (Catholic Charities, Heartland Family Service and Lutheran Family Services).

A care manager or employee from ENOA was in touch with the client either by phone or in person at least monthly. In addition, a “First Contact” volunteer from the Midland’s Chapter of the Alzheimer’s Association was assigned to interested caregivers.

As an outgrowth of the first grant, all caregivers received resource materials at intake and then monthly materials thereafter. The intake materials consisted of the *36 HourDay*, a three-ring binder (containing information about the disease, tips for caregivers and a listing of vendors agreeing to participate in the program), and, information about the Safe Return program (note: membership in the program was financed by the Midland’s Chapter of the Alzheimer’s Association). Caregivers also received information about newly added vendors, products to assist caregivers and helpful tips on assisting a person with Alzheimer’s disease. These materials were sent out with the monthly statements from ENOA.

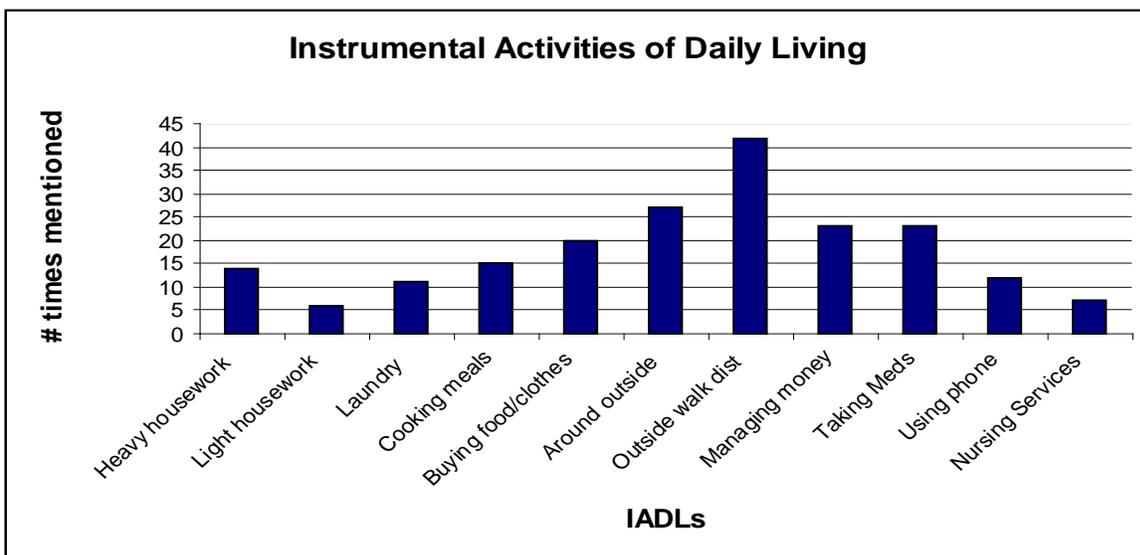
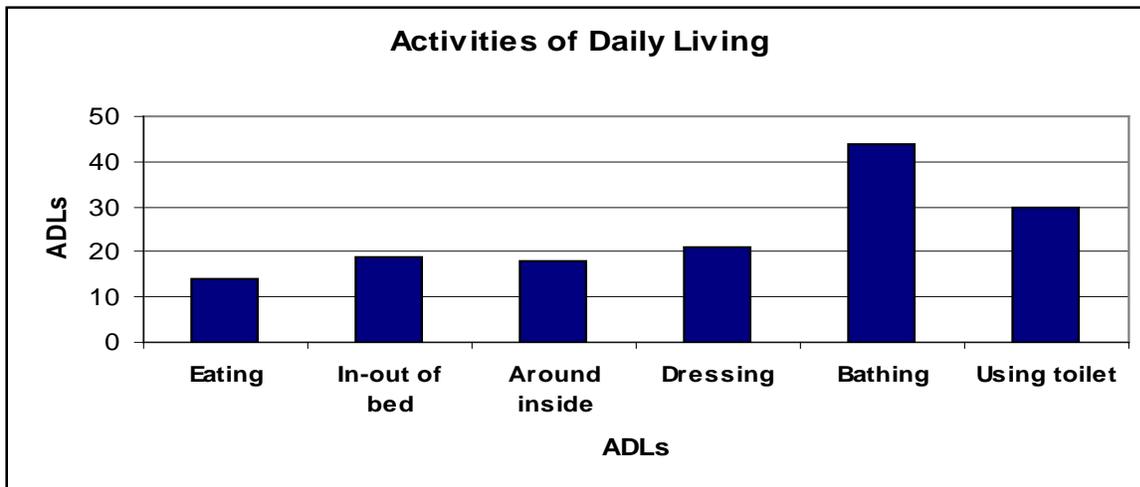
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**Challenges and Opportunities of Caregiving**

Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) serve as a way of understanding the burden faced by caregivers in their role. The graphs below highlight the tasks found to be most difficult when assisting a person with Alzheimer’s disease. Bathing was noted to be the most difficult for ADLs and going places outside walking distance was the most frequently mentioned for IADLs.

**Activities of Daily Living and Instrumental Activities of Daily Living (N = 86) (Exit Survey)**

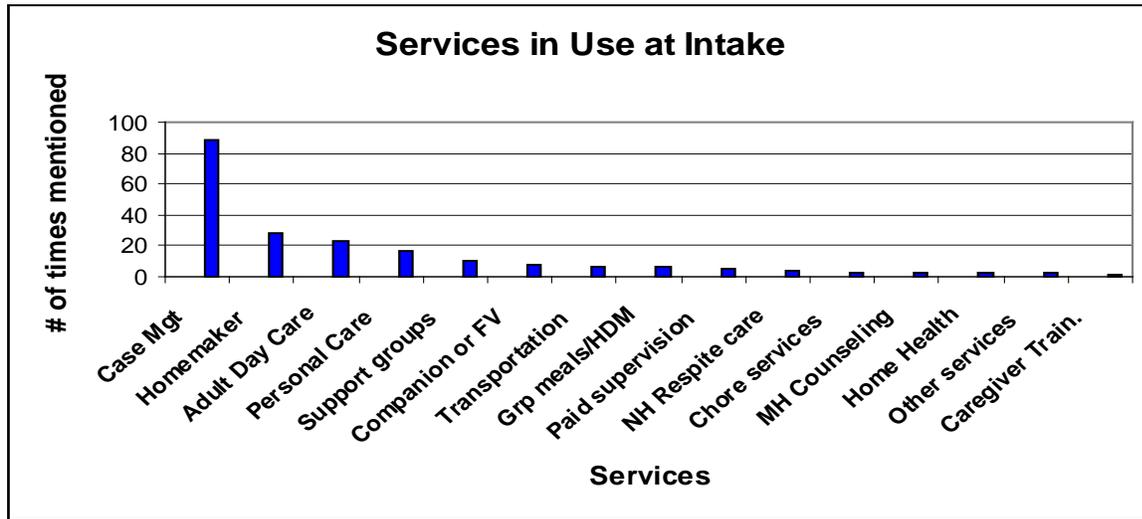
Caregivers were asked the following question: *Which tasks do you find the most difficult when assisting the care receiver?*



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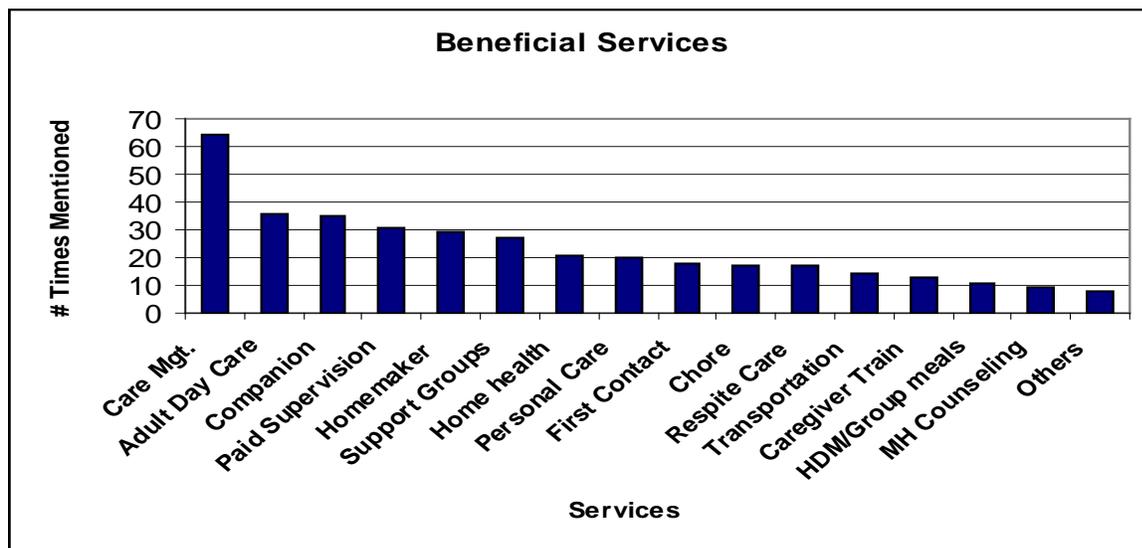
**Services in Use at Intake and at Discharge**

At intake, caregivers were asked to identify what services they were currently using to support the care receiver in the home. Services mentioned include:



**Beneficial Services Identified by Caregivers:**

As part of the exit survey, caregivers were asked the following question: *What services did you find most helpful in your caregiving role?* More services were mentioned by caregivers during the exit survey than at intake.



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## **Mental Health Services**

The availability of mental health services was an area of particular interest to the partners of this grant. Effort was made to create a relationship with local mental health providers to provide support to caregivers caring for someone with Alzheimer’s disease. Despite numerous attempts to make this service easy to access, caregivers opted not to use this service. It is interesting to note that the tool used to encourage the use of mental health services demonstrated the need – but did not motivate use.

<b>Mental Health Indicators (CES-D)</b>	<b>N</b>	<b>Mean Score</b>
Mood Score (CES-D) at intake	100	15.64 (unadjusted) SD = 8.96 Range 0-49
	100	16.33 (adjusted)* SD = 9.52 Range 0-49

The Center for Epidemiological Studies Depression Scale (CES-D) is a twenty-item instrument that has been used with various populations. It is an effective measure for identifying depression, especially in the older population. Scores range from 0 – 49. A score of 16 or greater on the CES-D would suggest depression.

\*In those instances where a form was not completed in its entirety, an adjusted score was created to account for the missing items.

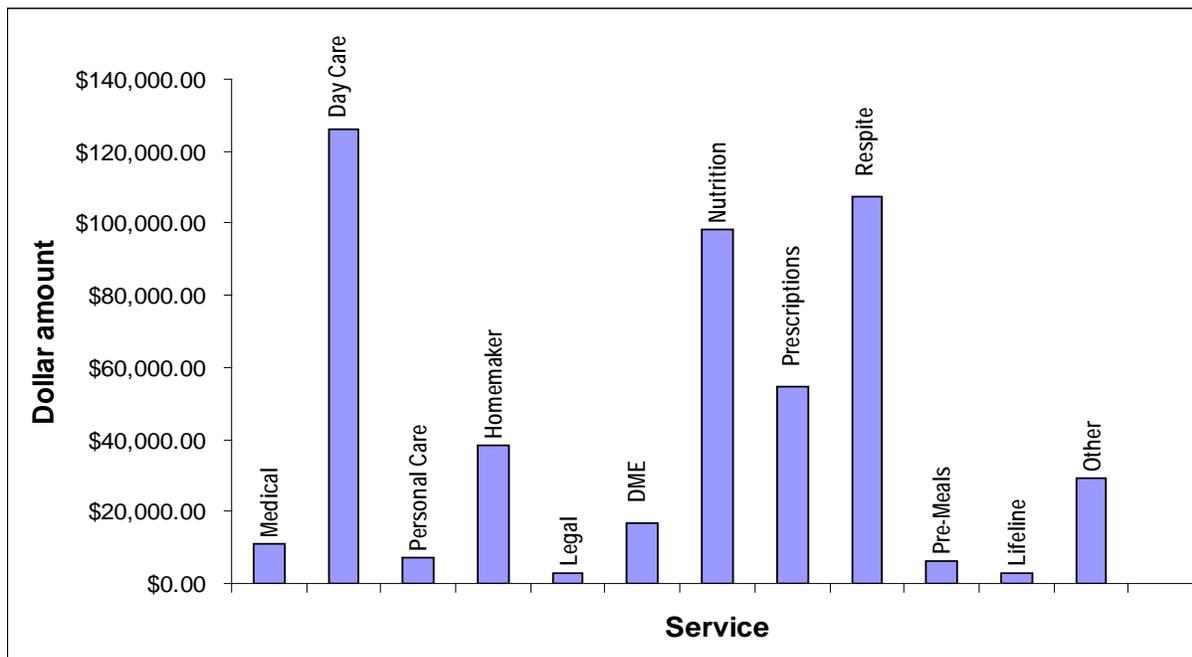
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**Goods/Services Purchased With Vouchers**

The primary purpose of this grant was to provide caregivers with money each month to purchase the goods or services they felt would best support their caregiving role. The consumer-directed nature of this grant is highlighted by the unique services selected by caregivers.

Note: Data in the graph below are based on a cumulative expense report created by Geri Urban (with ENOA) each month.

**2003 – 2006 Vouchers Payments by Type of Service Received**



Other services include: Miscellaneous purchases such as incontinence products, Ensure, sleeper beds, old movies, portable telephone, headboard/footboard, air conditioner - furnace repair, clothing, carpet cleaning, a lift chair, kitchen chairs and a washing machine.

**Gift Certificates**

Realizing the reluctance of some caregivers to use respite services, ENOA came up with the novel idea of offering gift certificates as an enticement to caregivers to “try out” adult day care and in-home support without having to draw from their monthly voucher allotment. Gift certificates were distributed during two caregiver parties held during 2005. A total of 58 caregivers redeemed gift certificates for respite or adult day care. The experience gave approximately 12 new caregivers the confidence to continue using the service on a regular basis.

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## **Overall Themes**

Several themes emerged from caregiver comments at the end of the exit survey. Caregivers were asked, “*Do you have any final comments about the grant/project?*” The themes identified by caregivers include the following:

- Financial help was welcomed by all persons, regardless of financial need (no means testing was used for this program). Caregivers found the voucher to be a useful tool to them in acquiring services.
- Caregivers had access to options other than nursing home care. The consumer directed approach of this grant gave caregivers the flexibility they needed to continue in their caregiving role by purchasing services such as respite and adult day care.
- The support of the Eastern Nebraska Office on Aging (ENOA) and the Midland’s Chapter of the Alzheimer’s Association was mentioned several times by caregivers as being beneficial to them in their caregiving role.
- There were some instances in which caregivers requested more hands-on support from the program while others felt the involvement of the care manager was sufficient. The needs of caregivers in this grant are, not surprisingly, very individualized.
- Although the program was promoted through various outlets, not all caregivers were made aware of the program. Caregivers mentioned the need for better publicity and/or information about the program.

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## **Lessons Learned**

Over the past three years a number of findings have come to light regarding the benefits of a voucher program for caregivers. As noted at the beginning of this report, the current program is an outgrowth of the findings from the initial AoA funding received in 2000 – 2003 for the state of Nebraska. The on-going availability of vouchers for caregivers, as well as the addition of mental health services and support from a First Contact Volunteer, gave the partners an opportunity to evaluate the effectiveness of these programs for caregivers supporting a family member with Alzheimer’s disease. The more relevant findings include:

- **Vouchers** - The modest income of clients (70 % had incomes less than \$20,000) and caregivers alike (47 % had incomes less than \$20,000) resulted in many using the vouchers for basic necessities such as groceries and medications. The availability of a voucher, regardless of the amount, gave these caregivers the strength to continue in their role of providing support in the home. Caregivers remarked of their interest in seeing this program continue – either for themselves, or, if their family member had died, for others to use. Policy makers need to be aware of the sacrifices family members are making to support their loved ones at home.
- **Delaying Nursing Home Placement** - This program was able to assist some family members in delaying placement in a nursing home by promoting the use of community based services, including adult day care and respite. Encouraging service use earlier on in the disease process has been found to be helpful in delaying institutionalization with persons having dementia in other studies (Zarit, Gaugler, & Jarrott, 1999). Effort was given to encouraging caregivers to use community based services by the care managers for this project.
- **Care Management** - Because of personnel changes with the care management agency, the availability of care managers for caregivers was not as readily available toward the end of the project as it had been during the first grant and the beginning of the second grant. Because caregivers rated case management services as being the most beneficial service to them, effort should be made to make care managers more accessible to caregivers for future projects.
- **Mental Health Services** - The reluctance of caregivers to use mental health services was disappointing, especially in light of the numbers of caregivers who had a depression score of 16 or greater on the CES-D (42 out of 100 caregivers completing the mood survey had an unadjusted score of 16 or greater at intake). There are a few possible reasons why the mental health component was not as successful as hoped.

First, a cohort effect may explain the resistance of caregivers to use mental health services. That is, older cohorts do not generally seek out mental health services. As such, it is not surprising they did not utilize this benefit. However, it is interesting that younger caregivers did not utilize this benefit either. Future programming should continue to offer this option as younger cohorts seem to be more amenable to using mental health services when compared to their parents and grandparents. Offering this service will require creative ways to encourage usage.

The second possible reason for the lack of service use could be due to caregivers relying on the care managers for their mental health support rather than turning to a mental health professional for assistance. While this was not the original intent, it is quite possible caregivers utilized the skills of the care managers in this manner. Perhaps future programming could pilot the use of a mental health practitioner, rather than a nurse, in the role as a care manager.

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**Mental Health (continued)**

Effort was made to encourage caregivers to use the mental health services offered through the grant. The mental health providers made themselves available to caregivers by attending and interacting at holiday parties for caregivers and the care recipients and offering home visits and phone calls. In addition, brochures and business cards of participating mental health professionals were sent with the monthly mailings to caregivers. Despite these efforts, the willingness of caregivers to use mental health services was not evident.

- **First Contact Volunteers** - A benefit of the program was to have access to a First Contact volunteer offered through the Alzheimer’s local chapter. For a variety of reasons the benefit of this program was not realized with this grant. Based on comments during the exit survey, future involvement of these volunteers should include more frequent contact – at least monthly - to sustain the emotional support intended for caregivers.
- **Support from Alzheimer’s Association** - The Alzheimer’s Chapter made every attempt to support caregivers in their role by underwriting the cost of the *36 Hour Day* and the Safe Return program. The *36 Hour Day* was most helpful to caregivers. Additionally, support groups and the monthly Chapter newsletters were mentioned by caregivers as being very useful to them. The on-going support of the Chapter was of value to caregivers throughout their experience with this grant.
- **Education about Alzheimer’s Disease** - Having access to information about the course of the disease as well as tips on how to successfully support a person with dementia was found useful by this group of caregivers. The more concise and to the point the materials the more suited they were for caregivers who did not have a great deal of time to devote to reading through volumes of material.
- **Creative Respite Options** - There were a few instances in which respite for the caregiver included such options as having a golf partner for the care recipient or a volunteer serving as a hockey companion. Both the caregiver and the care recipient were able to benefit from the flexibility of this program. Future programming should encourage such creative offerings.
- **Gift Certificates to Encourage Service Use** - Because some caregivers were hesitant to use the services available to them (out of concern of leaving care recipient with a stranger, or, wanting to save voucher money for a rainy day), ENOA took a creative approach in finding a way to encourage caregivers to use services. Three times during the funding period ENOA offered gift certificates to use for respite and/or adult day care which proved beneficial to twelve caregivers who were reluctant to use services in the past.

The positive reactions of caregivers to this program, as well as their willingness to continue to provide care to their family members, suggests a consumer directed program is useful for all. On-going efforts to secure additional funding from sources at the state and federal level and strengthened support of participating agencies and volunteers are in order to continue the good work that has started with this and all the other AoA demonstration grants.