

Annual Report 2013-2014

Department of Mental Health - Alzheimer's Respite Funding

Part 1B section 35 J12, Subsection 35.5

2013-2014 Budget

Presented to:

The Honorable Governor Nikki R. Haley

The Honorable Hugh K. Leatherman, Chairman Senate Finance Committee

The Honorable W. Brian White, Chairman House Ways and Means Committee

The South Carolina Department of Mental Health



Presented by:

alzheimer's  association®

South Carolina Chapter

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The Alzheimer's Caregiver Respite Assistance Program

On July 1, 2013, the Alzheimer's Association entered into a contract with the South Carolina Department of Mental Health to provide respite assistance to families in SC. We are pleased to report on the impact of these funds in the following pages.

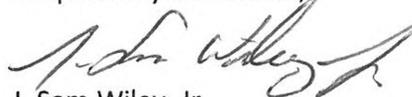
The Alzheimer's Caregiver Respite Assistance Program provides temporary relief to informal caregivers of persons with Alzheimer's or related dementia to help lessen the physical, emotional and financial burdens associated with intensive, long-term caregiving. The program allows family caregivers of someone with Alzheimer's disease (or related dementia) to access a minimum \$500 voucher per year, which can be used to arrange for short-term respite through approved in-home care agencies or adult day care centers, or to arrange a temporary stay in a long-term care facility. The cost of care is paid directly to the professional care agency or provider.

In 2013-2014, the Alzheimer's Association began a formal partnership with the Lieutenant Governor's Office on Aging (LGOA) and the 10 Regional Area Agencies on Aging (AAAs) to administer the Alzheimer's Caregiver Respite Assistance Program to families. This transition was a strategic move to ensure that people will have better access to services in South Carolina. It creates an avenue to ensure that families with Alzheimer's disease (and related dementia) are accessing important support services not only from the Alzheimer's Association but from the AAAs as well. A referral system between the Alzheimer's Association and the AAAs has been established in order to ensure families are benefitting from all available services. Furthermore, this transition allows the Alzheimer's Caregiver Respite Assistance Program to expand program delivery within our state's rural counties.

The Alzheimer's Association has been very pleased with the transition of program administration to the regional AAAs. We strongly believe that this arrangement will allow more families to be served more expediently, all the while reducing the duplication of services. In addition, this new partnership has strengthened collaboration among the Alzheimer's Association, the Regional AAAs and the LGOA, as we strive toward a shared goal of providing vital services to South Carolina's rapidly aging population.

The Alzheimer's Association, South Carolina Chapter, appreciates the opportunity to administer the Respite Assistance Funds to help meet the needs of caregivers across the state. We express our gratitude to members of the House of Representatives, Senate and the Governor for entrusting us with these funds.

Respectfully Submitted,



J. Sam Wiley, Jr.

Vice President of Programs
Alzheimer's Association
South Carolina Chapter

About Alzheimer's Disease and the Impact of Caregiving:

Alzheimer's disease is a progressive, degenerative disease that affects 79,000 individuals in South Carolina resulting in memory loss, personality change, decline in intellectual functioning and the loss of ability to take care of oneself. The incidence of Alzheimer's disease in South Carolina is expected to reach 120,000 by 2025 with most of these individuals being cared for in the home by an elderly spouse or adult child.

According to the *Alzheimer's Association 2014 Alzheimer's Disease Facts and Figures Report*, the number of Alzheimer's/dementia caregivers in South Carolina is over 291,000. The number of unpaid caregiver hours provided by these caregivers during 2013 was 331,000,000, which amounted to a dollar value of \$4,127,000. This significant contribution of family caregiving takes a toll on these dedicated individuals.

Fulltime caregivers provide 24 hour a day care for their loved ones often without taking a break. As a result, the caregiver's own physical and emotional health often suffers. They become more and more isolated as they pass up opportunities for social activities, stop going to church and stop visiting family and friends. The caregiver often neglects his or her own physical health by missing medical appointments, not seeing the dentist and giving up all forms of physical activity. The stress associated with caring for a loved one with dementia can be tremendous.

Studies indicate that 74% of dementia caregivers report that their own needs are unmet, and 66% report that their employment is adversely affected by their caregiving responsibilities. Fifty-five percent of dementia caregivers report having less time to spend with other family members.

Caregivers may become potential "secondary patients" because of the negative impact that providing care may have on their general health and risk for chronic disease, health-related physiological changes, health care utilization and even death. Research suggests that the chronic stress of caregiving may lead to conditions such as metabolic syndrome (a combination of abdominal obesity, high blood pressure, high blood glucose and high cholesterol that is often associated with developing diabetes and heart disease).

In addition, the incidence of depression in Alzheimer's caregivers is as high as 50%. Evidence suggests that elderly spousal caregivers who experience caregiver stress have a mortality rate 63% higher than average.

High caregiver stress leads to the increased need to seek long-term care placement for the individual with Alzheimer's disease. The goal of the Respite Assistance Program is to support family members in their role as caregivers to enable them to provide care in the home setting for as long as possible.

The need for respite care will continue as the elderly population dramatically increases. Funds received through the SC Department of Mental Health for this program allow the Alzheimer's Association to support family caregivers in a very significant way.

Summary of Program Delivery: Alzheimer's Caregiver Respite Assistance Program

During the course of the year July 1, 2013 - June 30, 2014 there were 1772 vouchers issued.

It should be noted that the Regional AAAs did not begin to issue vouchers until the last week of September 2013 (end of 1st quarter). During this time period an astonishing 341 vouchers were issued within a week's time. We have been actively involved in addressing emerging procedural challenges, which should become even smoother in the second year of the administrative transition.

Please note: During the 1st quarter of the administrative transition, we noticed an under-reporting of county and other demographics (reflected as Unknown in the breakdowns below). We were able to resolve this data collection oversight through procedural changes in the 2nd quarter.

Vouchers Issued by County	
Abbeville	2
Aiken	126
Allendale	6
Anderson	68
Bamberg	12
Barnwell	6
Beaufort	113
Berkeley	43
Calhoun	9
Charleston	121
Cherokee	88
Chester	19
Chesterfield	4
Clarendon	14
Colleton	24
Darlington	20
Dillon	12
Dorchester	29
Edgefield	2
Fairfield	3
Florence	34
Georgetown	24
Greenville	46

Greenwood	37
Hampton	19
Horry	132
Jasper	21
Kershaw	8
Lancaster	16
Laurens	23
Lee	4
Lexington	27
Marion	17
Marlboro	7
McCormick	3
Newberry	4
Oconee	20
Orangeburg	58
Pickens	29
Richland	59
Saluda	1
Spartanburg	90
Sumter	55
Union	11
Williamsburg	18
York	83
Unknown	205

The clients served through vouchers issued during the fiscal year displayed the following characteristics:

New Clients vs Renewals	
New Clients	1388
Renewals	338
Unknown	46

Age	
18-59	78
60- Over	1672
Unknown	22

Gender	
Male	671
Female	1065
Unknown	36

Race	
Caucasian	1051
African American	672
Other	43
Unknown	6

Ethnicity	
Hispanic or Latino	8
Non-Hispanic or Non-Latino	1402
Unknown	362

Type of Service Utilized	
In-home	1345
Facility Stay	65
Daycare	167
Group Respite	28
Unknown	167

Respite Usage & Outcomes:

Caring for an individual with Alzheimer's disease has been cited as one the most difficult of all of life's demands. Respite care is indicated as a key intervention for helping to reduce caregiver stress and related health risks while increasing the caregiver's ability to manage the caregiving situation. Without intervention, the expectation would be for the caregiver stress level to increase as the disease progresses and the demands of caregiving increase.

Caregivers are surveyed to determine the impact of the program. As a result of new procedures in this transition year, the sample of caregivers providing survey responses was smaller than our typical pool of participation. To provide additional context, we've provided survey results from both 2013-2014 and 2012-2013.

2013-2014	2012-2013	Survey Components
100%	99%	Agree or strongly agree that it made their caregiving situation more manageable.
100%	99%	Agree or strongly agree that it reduced the caregiver's stress level.
100%	97%	Agree or strongly agree that it allowed them to get out and take a break from caregiving according to their needs
100%	94%	Agree or strongly agree that it helped them take care of themselves.
100%	91%	Agree or strongly agree that it was a positive experience for their family member.
100%	95%	Agree or strongly agree that it has helped them to be an effective caregiver.
100%	97%	Agree or strongly agree that they have been satisfied with the quality of care provided through the program.

Families use their respite care hours for a variety of purposes such as attending medical appointments, attending church, taking care of business matters, visiting family and friends, grocery shopping or simply to rest. Occasionally caregivers use the time to take a short family vacation with the knowledge that their loved one is receiving good care. In some instances, these funds are used for emergency care if the caregiver becomes ill, must have surgery, or if a family emergency occurs.

Caregivers from throughout the state participate in the program. Efforts are made to involve all respite care clients in other Alzheimer's Association programs such as support groups, educational offerings, the wanderer's identification program and other programs. Families are also encouraged to continue utilizing respite services on their own after voucher funds are depleted.

Financial Summary:

The previous pages lists the demographics of direct grants allocated to participants. The total value of \$500 grants issued during the fiscal year total \$886,000 which exceeds the \$700,835.40 total allocated for direct grants. These additional allocations were allowed based on the fact that a significant number of vouchers issued are never used in their entirety due to permanent long term care placement, death or other family situations. These unused funds are made available for other families to use. Records are maintained to track which respite grants are used, partially used or never used in order to know how much remains for reallocation.

As specified in the SCDMH Contract, 10% of the total funds received are used to administer the program. This amount was \$77,870.60 for the 2013-2014 fiscal year. These funds were allocated to the 10 Area Agencies on Aging to assist with administration of the respite voucher funds. This allocation was based on need in each area and conformed to the formula currently used by the Office on Aging to allocate Family Caregiver Support Program funds among the Area Agencies on Aging.

With 291,000 unpaid Alzheimer's caregivers in South Carolina, the need for the Alzheimer's Caregiver Respite Assistance Program grows consistently each year, outstripping availability of current funds.

Planned improvements for 2014-2015:

We have learned a great deal in this transition year, and we will continue to improve the administration of the Alzheimer's Caregiver Respite Assistance Program in the following ways:

Streamlined respite applications

This fiscal year the Alzheimer's Association will work with the LGOA and the AAAs to streamline the respite application statewide in order to enhance the efficiency of the application process and to reduce printing and mailing costs. This will also simplify the application experience for the family caregivers seeking to access this and other programs.

Strengthened Caregiver Satisfaction Surveys

The Alzheimer's Association will work to strengthen procedures for issuing caregiver satisfaction surveys in order to learn from the participants' experience and respond to emerging needs or concerns. Through discussion with the LGOA/AAAs, we will assess current surveying methods with an eye toward maximizing caregiver participation in the survey while minimizing administrative expenses such as postage.

Improved Data Collection

It should be noted that at the beginning of the administrative transition, the primary focus of all parties was to begin serving families as quickly as possible. During the first quarter of the FY 13-14 year, the AAAs did not capture vouchers issued by counties; this oversight was corrected in the 2nd quarter. While the AAAs are currently collecting the requisite data needed for a thorough report, the Alzheimer's Association plans to provide more focus and support to the LGOA and AAAs to strengthen data collection for future reporting purposes.

How Alzheimer's Caregiver Respite Fits into the Big Picture of Respite in South Carolina:

The Alzheimer's Caregiver Respite Assistance Program is one of three distinct programs being administered by the 10 Area Agencies on Aging (AAAs) in South Carolina. Once a family uses their entire Alzheimer's Association voucher, they could potentially receive additional assistance from either the Family Caregiver Support Program (a federal-state match program established through the Older Americans Act) or State Respite Funds (secured by former Lt. Governor McConnell in recent years).

However, the latter two programs have more stringent criteria and many families may not be eligible for assistance through them -- which is part of why the Alzheimer's Caregiver Respite Assistance Program is so important to South Carolina families. By administering all three of these programs, the 10 Area Agencies on Aging are ideally situated to work with families to determine the most appropriate source of assistance, based upon eligibility factors, availability of funds and the unique needs of the family.

Organizational History:

The Alzheimer's Association, SC Chapter provides support and services to individuals with Alzheimer's disease and related disorders and their families. Services include the respite assistance program, support groups for caregivers and individuals in the early stage of Alzheimer's disease, a help line, a wanderer's identification program, information and guidance, care consultation, educational programs and training for family and professional caregivers. Services are offered at no charge to families with the exception of the wanderer's identification program, which is also provided at no cost if a family is unable to pay.

The Alzheimer's' Association began its work in South Carolina in the mid 1980's in response to the needs of caregivers who were looking for information, guidance and support. Prior to 1980 when the national association was founded, there was little information about Alzheimer's disease and the problem was often misdiagnosed. With the increase in awareness, a small group of caregivers committed themselves to forming a local chapter, which could serve the needs of the community.

In October 2006, the Upstate SC Chapter and the Palmetto Chapters in South Carolina merged to form the South Carolina Chapter. As one statewide chapter, the organization is able to move forward providing services more efficiently and effectively in all 46 counties of the state. The SC Chapter is one of 83 chapters located throughout the country. It is governed by a 19 member voluntary board of directors. The headquarters of the SC chapter are located in Anderson, SC with area offices located in Greenville, Spartanburg, Columbia, Charleston and Myrtle Beach.

The mission of the Alzheimer's Association is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. Our vision is a world without Alzheimer's.