

Annual Report 2016-2017

Department of Mental Health - Alzheimer's Respite Funding

Part 1B section 35 J120, Subsection 35.3

2016-2017 Budget

Presented to:

The Honorable Governor Henry McMaster

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 Program

On July 1, 2016, the Alzheimer's Association entered into a contract with the South Carolina Department of Mental Health to provide respite assistance to families who are providing unpaid care for a family member with Alzheimer's or related dementia. This program was funded at \$900,000 in the state's 2016-2017 budget. We are pleased to report on the impact of these funds in the following pages.

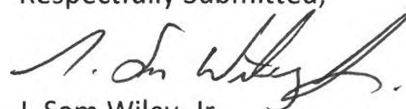
For over a decade, the Alzheimer's Caregiver Respite Program has provided temporary relief to informal caregivers of persons with Alzheimer's or related dementia to help lessen the physical, emotional and financial burdens associated with intensive, long-term caregiving. The program allows family caregivers 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 in-home care agencies, private-duty caregivers, adult day care centers, or a temporary stay in a care facility. The cost of care is paid directly to the professional care agency or provider.

In 2013, 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 document reports on the third year of this partnership, which has created 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. This partnership has allowed 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 program administration provided by the regional AAAs. We strongly believe that this arrangement allows more families to be served more expediently, all the while reducing the duplication of services. In addition, this 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 Department of Mental Health, the SC General Assembly 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 86,000 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 2017 Alzheimer's Disease Facts and Figures Report*, there are 304,000 Alzheimer's/dementia caregivers in South Carolina. During 2016, these unpaid caregivers provided an estimated 347,000,000 hours of informal care, which is valued at over \$4.3 billion. This significant contribution takes a toll on these dedicated individuals, and caregiver stress can lead to the increased need to seek long-term care placement for the individual with Alzheimer's disease or other dementia.

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. Family caregivers are our first line of defense before higher and more costly levels of care are needed.

From a budgetary standpoint, it's important to note that South Carolina is expected to see a 45.8% increase in Medicaid long term care costs for people with Alzheimer's or related dementia, from \$544 million in 2017 to \$793 million in 2025. This is the 13th highest projected increase in the nation.

Nationally, seniors with Alzheimer's and other dementias rely on Medicaid at a rate nearly three times greater than other seniors. The national average per-person Medicaid costs are 23 times higher for Medicare beneficiaries with Alzheimer's and other dementias: \$8,182 per person for individuals with Alzheimer's and other dementias compared with \$349 for individuals without the disease.

Respite is a practical and cost-effective means of supporting caregiver well-being, potentially avoiding or postponing strain on the state budget as families turn to Medicaid long term care.

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.

Beyond simply issuing respite vouchers, 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.

The Burden of Dementia Caregivers:

Fulltime caregivers provide round-the-clock care for their loved ones, often without taking a break. As dementia progresses, the care required of family members can result in increased emotional stress and depression, new or exacerbated health problems, and depleted income and finances due in part to disruptions in employment and paying for health care. Caregivers may become potential "secondary patients," neglecting their own physical health by missing medical appointments, giving up physical activity, and eating less healthfully. 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 stress associated with caring for a loved one with dementia can be tremendous. According to the *Alzheimer's Association 2017 Alzheimer's Disease Facts and Figures Report*:

- Compared with caregivers of people without dementia, twice as many caregivers of people with dementia indicate substantial financial, emotional and physical difficulties.
- 59% of family caregivers of people with Alzheimer's and other dementias rate the emotional stress of caregiving as high or very high.
- 30-40% of family caregivers of people with dementia suffer from depression, compared with 5- 17% of non-caregivers of similar ages. Rates of depression increase with the severity of cognitive impairment of the person with dementia.
- 1 in 3 caregivers of people with Alzheimer's or another dementia report that their health has gotten worse due to care responsibilities (35%) compared with 19% of caregivers of people without dementia.
- Among people who were employed in the past year while providing care to someone with Alzheimer's or another dementia, 15% quit their jobs or retired early due to their care responsibilities. 57% reported sometimes needing to go in late or leave early, and 16% had to take a leave of absence.

We are fortunate to have state-specific data on dementia caregivers, collected by the SC Department of Health and Environmental Control via the 2015 Behavioral Risk Factors Surveillance System, a telephone survey implemented nationwide each year to evaluate the impact of public health issues on our state. This data, provided on the next page, further demonstrates the unique needs of dementia caregivers in South Carolina.



dementia caregiving in south carolina

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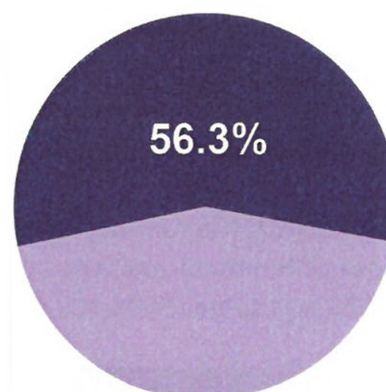
DATA FROM THE 2015 BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM

In South Carolina, more than half of all adults providing unpaid care to loved ones with Alzheimer's or another dementia have been doing so for at least two years.

More than one-third of Alzheimer's and dementia caregivers provide 20 or more hours of care per week.

Nearly one in three dementia caregivers are in the "sandwich generation" – caring for both someone with dementia and a child or grandchild.

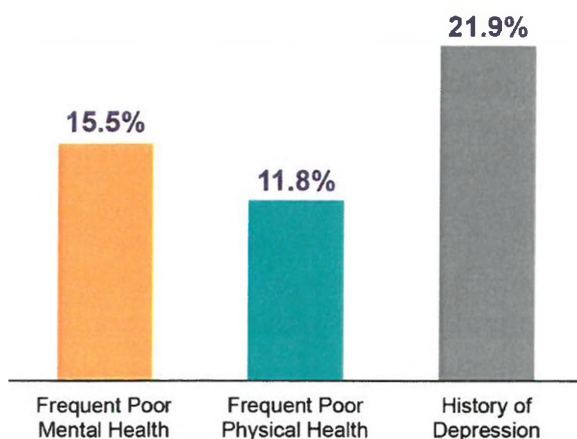
Percent of dementia caregivers providing care for at least 2 years



Characteristics of Alzheimer's and Other Dementias Caregivers

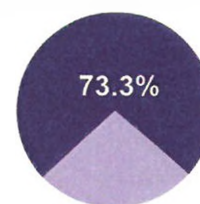
Gender		Age		Hours of Care per Week		Caring for Parent or Parent-in-law	Also Caring for Minor
Women	Men	45-64	65+	20+	40+		
53.5%	46.5%	46.3%	19.2%	35.7%	26.9%	54.2%	32.1%

Impact of Alzheimer's and dementia caregiving



Percent who manage household care, such as cleaning or cooking

Percent who manage personal care, such as feeding or bathing



This Fact Sheet is supported by Cooperative Agreement #NU58DP006115 from the Centers for Disease Control and Prevention (CDC). Its contents are solely the responsibility of the Alzheimer's Association and do not necessarily represent the official views of the CDC.

The Big Picture of Respite in South Carolina:

With 304,000 unpaid Alzheimer's caregivers in South Carolina, the need for the Alzheimer's Caregiver Respite Assistance Program grows consistently each year, frequently outstripping availability of funds. Fortunately, this is one of three distinct respite programs being administered by the Area Agencies on Aging (AAAs) in South Carolina, including the Family Caregiver Support Program (a federal-state match program established through the Older Americans Act) and State Respite Funds (secured by the Lt. Governor's Office on Aging in recent years).

While the latter two programs are available to eligible family caregivers, the Alzheimer's Caregiver Respite Program is unique in its ability to serve those affected by Alzheimer's or related dementia; any South Carolinian with doctor's statement of a dementia diagnosis is eligible for assistance. By administering all three of these programs, the 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.

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

During 2016-2017, the funding for this program (\$900,000) was authorized in its entirety.

At the close of the fiscal year, the Lt. Governor's Office on Aging reported that a total of \$776,047.26 was spent: \$696,402.16 in program funds and \$79,645.10 in administrative funds.

Funds Spent by AAA Region	
Region	Program funds
Appalachia	\$117,926.06
Upper Savannah	\$28,642.56
Catawba	\$67,940.16
Central Midlands	\$86,742.27
Lower Savannah	\$84,230.89
Santee-Lynches	\$69,599.26
CareSouth	\$39,021.79
Waccamaw	\$51,276.35
Trident	\$77,475.79
Lowcountry	\$73,547.03
TOTAL SPENT	\$696,402.16

The unspent program funds may be attributed largely to challenges ensuring that caregivers use their respite vouchers within the established timeframe. Inevitably, a 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 typically reallocated for other families to use at the beginning of the next fiscal year. Staff turnover may also contribute to this challenge.

As specified in the SCDMH Contract, 10% of the total funds received are used to administer the program. This amount was \$90,000 for the 2016-2017 fiscal year, of which just \$79,645.10 was spent by 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 State Respite funds among the Area Agencies on Aging. We appreciate that these administrative funds were spent conservatively.

During the course of the year July 1, 2016 - June 30, 2017 there were 1,332 vouchers issued.
The statewide average of the voucher value issued is \$736.

Vouchers Issued by County*	
Abbeville	7
Aiken	67
Allendale	2
Anderson	31
Bamberg	7
Barnwell	8
Beaufort	36
Berkeley	35
Calhoun	2
Charleston	124
Cherokee	11
Chester	25
Chesterfield	18
Clarendon	13
Colleton	21
Darlington	36
Dillon	9
Dorchester	43
Edgefield	3
Fairfield	6
Florence	64
Georgetown	23
Greenville	72

Greenwood	25
Hampton	18
Horry	99
Jasper	13
Kershaw	12
Lancaster	49
Laurens	16
Lee	5
Lexington	23
Marion	13
Marlboro	8
McCormick	3
Newberry	5
Oconee	17
Orangeburg	35
Pickens	19
Richland	49
Saluda	5
Spartanburg	51
Sumter	50
Union	23
Williamsburg	13
York	118

Client Demographics

The clients served this fiscal year displayed the following characteristics:

New vs. Returning Participants	
New Clients	866
Renewals	466

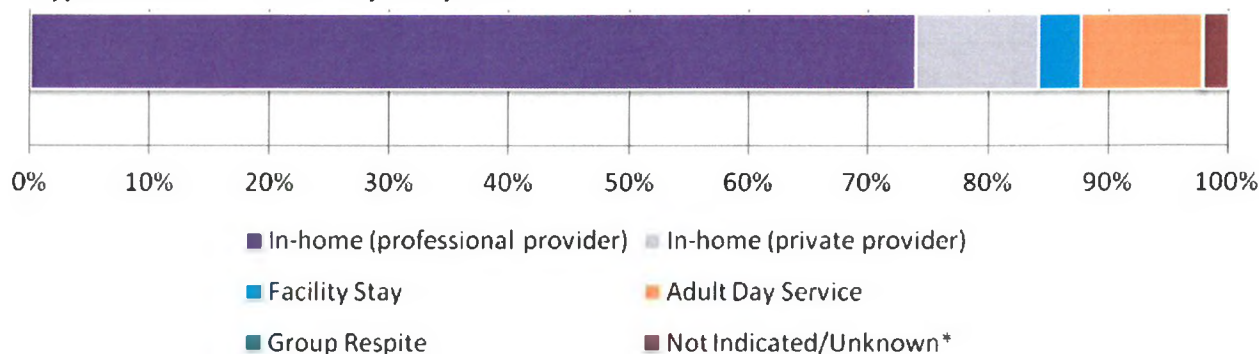
Gender	
Male	491
Female	841

Age	
18-59	119
60- Over	1,213

Ethnicity	
Hispanic or Latino	16
Non-Hispanic/Non-Latino	1,311
Unknown	5

Race	
Caucasian	762
African American	548
Other	22

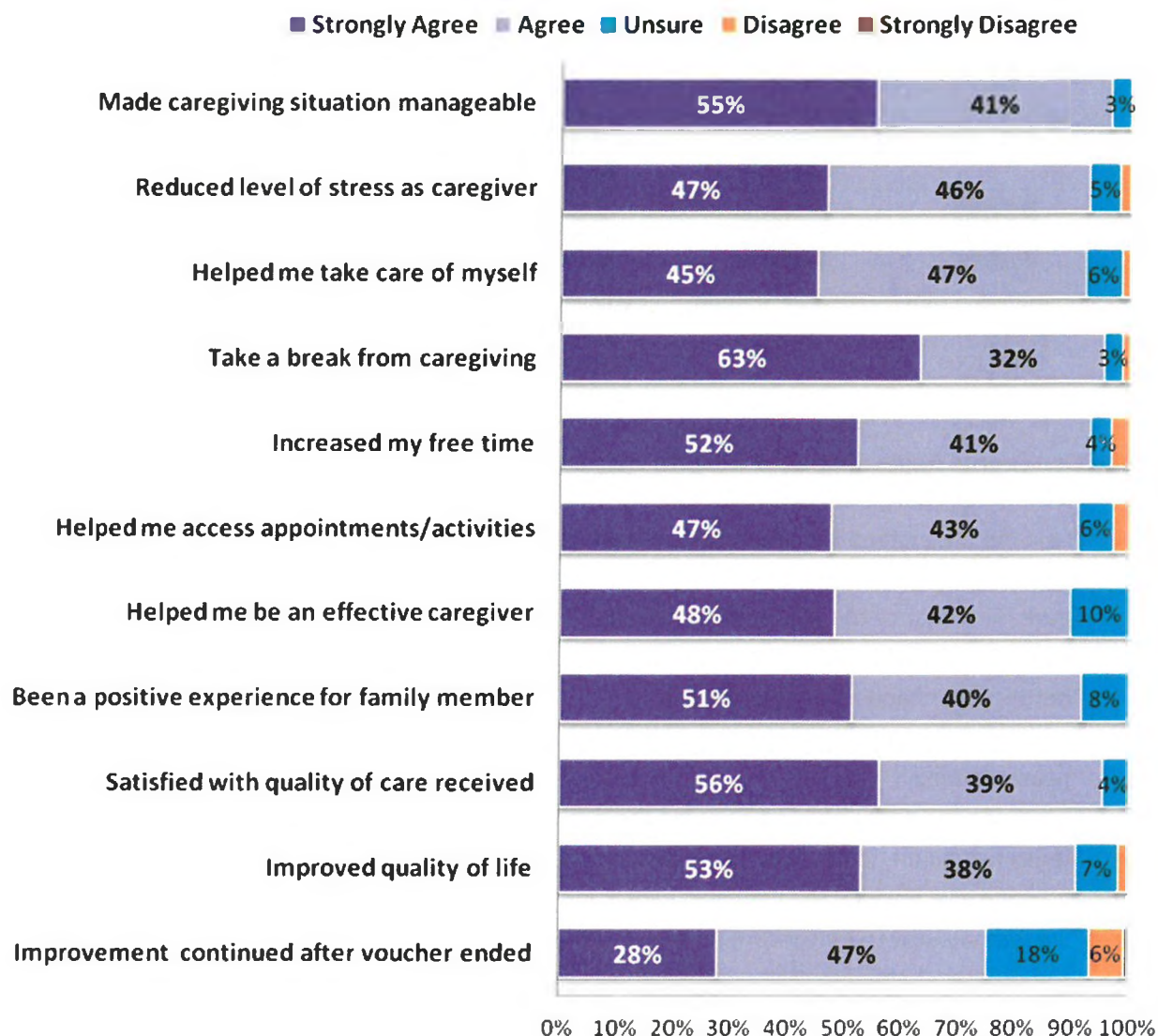
Type of Service Utilized by Recipients



*In some cases the type of service utilized by voucher recipient was not available at the time of reporting. This most likely reflects scenarios in which the voucher recipient had not yet determined the type of service they planned to utilize at the time the voucher was awarded. Once the voucher recipient decided on the type of service at a later date, internal staff did not go back to record service in records for reporting.

Outcomes of Respite Usage:

To ensure that utilization of respite services results in measurable outcomes, caregivers are surveyed to determine the impact of the program. 237 surveys were collected from across the state. The following results were recorded for the 2016-2017 fiscal year:

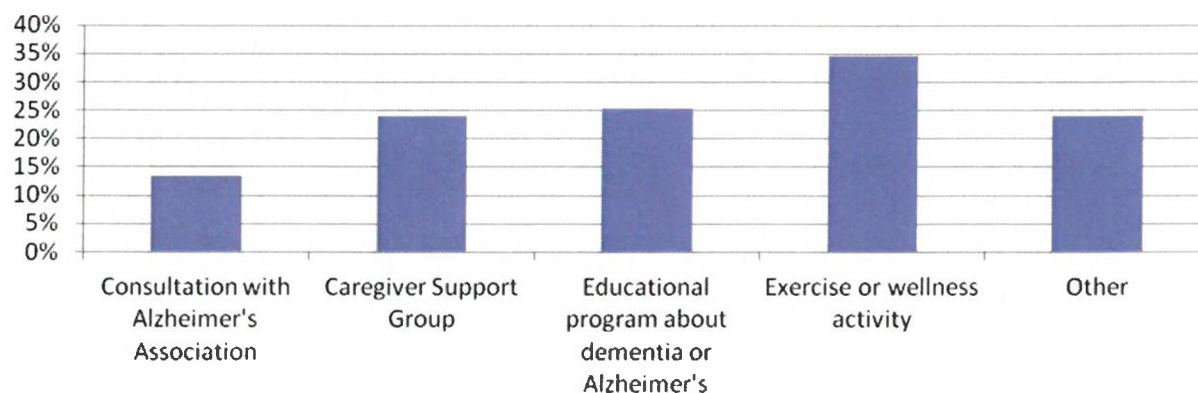


Survey Respondents Suggestions for Improvement

- 23 suggested that the voucher last longer than 3 months
- 23 suggested more funding per voucher
- 9 suggested more consumer choice between professional vs. private providers
- 8 suggested more awareness of the respite program

Survey Respondents Taking Part Enrichment Activities (In Addition to Respite)

Survey respondents were also asked whether they have participated in any enrichment activities during the last four months to further assist in promoting caregiver health. While we would like to see greater numbers of respite recipients taking advantage of support services or engaging in wellness activities, it is encouraging to see that many are taking positive steps.



Survey Comments Regarding How Respite Helped

- "a tremendous help in family social life."
- "help me understand the importance of taking a break providing care even once the voucher was not available."
- "gave me a chance to take catch my breath."
- "help me be a better caregiver."
- "better understanding of how to deal."
- "without respite care my mom would be in a nursing home."
- "peace of mind."
- "has given me peace of mind knowing there is support where needed."
- "it has helped me to be able to spend some quality time with family members."
- "help me give my wife the very best care."
- "we learned how to better care for our love one."
- "the program helped to relieve some of the anxiety of my daughter, who works long hours, and who worries about me, 78 years old, and her grandmother, 103 years old, may fall or get sick at home."
- "allowed me to breath."
- "I am the only child, it allowed me to get out and take a break."
- "I am a better caregiver after receiving this opportunity to have time off."
- "I was able to make work on time, did not have to call off work."
- "by giving me a break I could offer more care for Dad."
- "allowed me to go to cardiac therapy, and buy groceries, etc..."
- "...a few hours away makes me more patient and a better caregiver."
- "I could go to my grandson's graduation from college and not worry about my husband being cared for."
- "allowing a 76 year old caregiver to have much needed respite enables me to be a better caregiver."

About the Alzheimer's Association:

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 24-Hour Helpline (800-272-3900), 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.

As of July 1, 2017, the South Carolina Chapter has legally merged with the national Alzheimer's Association, but the chapter continues its leadership, advocacy and program delivery here within the state. The statewide chapter serves the entire state of South Carolina through a network of local offices located in Anderson, 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.

