

Alzheimer's Resource Coordination Center

Annual Report

July 1, 2014 through June 30, 2015

Presented to the

**South Carolina General Assembly
June 1, 2016**

**Lieutenant Governor's Office on Aging
Alzheimer's Resource Coordination Center
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EXECUTIVE SUMMARY

In 1994, the state legislature created the Alzheimer's Resource Coordination Center (ARCC) in response to the recommendations of the Blue Ribbon Task Force on Alzheimer's disease in South Carolina. The mission of the ARCC is to improve the quality of life for persons with Alzheimer's disease or related dementias (ARD), their families and caregivers through planning, education, coordination, advocacy, service system development and communication. It is guided by a twenty-three member Advisory Council appointed by the Lieutenant Governor. The Advisory Council includes representatives from state agencies, professional organizations, universities, and caregivers with an interest in providing and improving care and services for the population.

The 2013-2014 SC Alzheimer's Disease Registry Annual Report identified 90,040 persons in South Carolina living with a diagnosis of dementia as of January 1, 2012. The Registry tracks information from January 1, 2012 through December 31, 2012, the most current period with available and comprehensive data. In 2015 in South Carolina, approximately 300,000 persons care for these individuals (based on statistics provided by the Alzheimer's Association "2016 Alzheimer's Disease Facts and Figures"). The Alzheimer's Association report projects a 43% increase in the number of persons affected by Alzheimer's disease and other related dementias between 2016 and 2025. A recent study by the National Institute on Aging suggests that those numbers may be higher since the declining death rate after age 65 may mean that more people will survive to the oldest ages (after 85) where the risk for Alzheimer's disease and other disorders is the greatest. Therefore, this is an issue of growing concern and underscores the need for development of community-based services.

In the United States, more than 15 million family and friends provided un-paid in-home care in 2015 (Alzheimer's Association "2016 Alzheimer's Disease Facts and Figures"). In 2015, nearly 341 million hours of unpaid care was reported by those caring for an individual with Alzheimer's or other dementia. The estimated value of care by family and unpaid caregivers in South Carolina alone was over \$4 billion in 2015 (Alzheimer's Association "2016 Alzheimer's Disease Facts and Figures"). The physical, emotional, and financial demands on unpaid caregivers are huge, especially for those caring for a person with dementia. Sixty percent of family caregivers of people with Alzheimer's and other dementias rated the emotional stress of caregiving as high or very high. Moreover, approximately 40 percent of family caregivers of people with Alzheimer's and other dementias report symptoms of depression (Alzheimer's Association "2016 Alzheimer's Disease Facts and Figures"). Families want to keep their loved ones at home. However, the absence of supportive services which enable families to care for their loved ones at home may lead to premature placements in an institutional setting, thereby increasing the economic cost to the state and the psychological cost to the family caregivers.

The Alzheimer's Disease Registry reports that of the 90,040 persons currently living with Alzheimer's disease or a related disorder in South Carolina, 24,208 (29%) are known to reside in nursing homes and 61,244 (68%) reside in the community, while another 4,588

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(5%) live in unknown location. The 2015 Genworth “Cost of Care” Survey estimates the average nursing home cost for a private room in South Carolina is \$75,008 annually, while the median home health aide costs \$19 an hour. Nursing home cost in areas like Charleston and Columbia are even higher with an average of \$85,775 annually. Based on these figures the cost per day to live in a private room at a nursing home is nearly double that of having a home health aide. Most persons with Alzheimer’s disease are cared for at home by family members who provide care at great cost to their own physical and emotional health as well as their financial status. A large portion of this cost is borne by the Medicaid program. Families or informal caregivers also pay for a considerable portion of this cost. In 2015, the Medicaid cost of caring for people with Alzheimer’s in South Carolina was \$561 million. South Carolina must find ways to assist and support caregivers in maintaining their loved ones and friends at home as long as possible in order to avoid or delay institutionalization.

Caregivers of persons with Alzheimer’s disease in South Carolina have identified their top three needs:

1. Caregiver support, in the form of emotional support, family support and support groups;
2. Information and resources on the disease; and
3. Respite services which allow caregivers to take a short break from their 24/7 care giving responsibilities.

A major barrier to proper care and services for individuals in South Carolina has been the lack of resources to fund the continuum of services needed by families through the course of the progressive disease.

The Legislature has addressed this need by allocating \$150,000 in state funds to the ARCC each year to develop community-based respite programs, caregiver education and training, and other supportive services to caregivers of persons with Alzheimer’s disease and related disorders. Since 1995 small seed grants have been awarded to communities for dementia-specific respite and educational programs. These programs include group respite, in-home respite, and a voucher-based respite program (?) in which consumers can choose the type of respite that best meets their needs. Education programs target primarily family caregivers, and may include persons with Alzheimer’s disease, the medical community, colleges and universities, first responders, such as police, fire and emergency medical personnel, and the general public. Recipients of the grants are required to equally match state grant funds through cash or in-kind match.

The ARCC is the only entity in South Carolina that awards grants to start dementia specific respite and education programs in communities. It monitors and provides technical assistance to grantees to ensure that the standards remain at the highest level. It offers information and resources to the grantees as well as the general public. The ARCC continues to encourage and support grantees after their grant award has ended by offering technical assistance to encourage the sustainability of their programs.

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Alzheimer’s disease is one of the costliest and most uninsured health risks South Carolina families are likely to face. With the Baby Boomers aging and with in-migration, South Carolina’s senior population is going to drastically increase. With the increase in the numbers of seniors and the increase in life expectancy, the impact of Alzheimer’s disease on families, government and businesses may reach epidemic proportions. By preparing for the future now and providing the much-needed supportive services for families caring for loved ones at home, South Carolina will be ready to meet the challenges of Alzheimer’s disease and related disorders with programs and services in place, rather than trying to handle the epidemic after it has started.

Support Services Provided By ARCC Grantees in 2014-2015:

Number of Unduplicated Respite Participants	51
Hours of Respite Provided	8,889
Number of Training and Education Sessions	299
Number of Attendees – Training and Education	4868
Number of Outreach Events	84
Number of Attendees – Outreach Events	3,161
Number of support groups	196 ¹
Number of Attendees – Support Groups	2,514 ¹

Seven grants were awarded in 2014-2015, comprised of four respite programs and three education programs. All ARCC grant awards are equally matched with community funding and resources. A plan is required for continuation of the program after grant funding is discontinued. Standardized reporting for all grant programs is required to aid in ensuring fidelity to the objectives as outlined in the grant application.

As part of the grant process, the ARCC sponsored a pre-proposal workshop for prospective grantees in February 2015 and a grant procedures workshop for new grant recipients in June 2015. Additionally, ARCC grant information is made available at www.aging.sc.gov.

Providing the much-needed supportive services for families caring for loved ones at home can prevent or delay the much higher cost of assisted living or nursing home placement. A substantial cost savings is realized for both the state and its taxpayers when home- and community-based services are adequately funded and available for utilization. Support from our state’s leaders is imperative in combating the costs associated with these diseases. By acting proactively, our state will spend less money and serve more victims of Alzheimer’s and related disorders. If our leadership fails to act, taxpayers will be forced to foot the bill for the huge differences in costs. We thank the South Carolina Legislature for its support in providing relief, respite, and education to South Carolinians with Alzheimer’s disease and related disorders and their caregivers, and we believe

¹ Totals include only those grantees that provided in-house support groups.

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further investigation of the savings our state will see by supporting home and community based services is warranted. Due to the unprecedented growth of the senior population in our state, it is vital to our state's welfare, our citizens, and our economy that our leadership studies these potential savings that could very well avert a crisis in our state.

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I. Background

A. Enabling Legislation

The Alzheimer's Resource Coordination Center was created in the Division on Aging (now the Lieutenant Governor's Office on Aging) by act of the South Carolina Legislature effective April 20, 1994. The purpose of the Center is to "provide statewide coordination, service system development, information and referral, and caregiver support services to individuals with Alzheimer's disease and related disorders, their families, and caregivers."

B. Responsibilities Assigned by Legislation

According to the SC Code of Laws Section 33-36-320, the center shall:

- (1) initiate the development of systems which coordinate the delivery of programs and services;
- (2) facilitate the coordination and integration of research, program development, planning, and quality assurance;
- (3) identify potential users of services and gaps in the service delivery system and expand methods and resources to enhance statewide services;
- (4) serve as a resource for education, research, and training and provide information and referral services;
- (5) provide technical assistance for the development of support groups and other local initiatives to serve individuals, families, and caregivers;
- (6) recommend public policy concerning Alzheimer's Disease and related disorders to state policymakers;
- (7) submit an annual report to the Joint Legislative Committee on Aging and to the General Assembly.

C. Community Grants

According to the SC Code of Laws Section 44-36-325, the Alzheimer's Resource Coordination Center was further directed to "develop a grant program to assist communities and other entities in addressing problems relative to Alzheimer's disease and other related disorders. In awarding grants, consideration must be given to recommendations made by the advisory council to the center on priority needs and criteria for selecting grant recipients. As a condition to receiving a grant, the community or other entity shall provide matching funds or an in-kind contribution equal to the amount of funds awarded in the grant." This act took effect July 1, 1996.

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II. ADVISORY COUNCIL

The ARCC is supported by an advisory council appointed by the Lieutenant Governor including, but not limited to, representatives of:

1. Alzheimer's Association – SC Chapter
2. AARP
3. Clemson University
4. Department of Disabilities and Special Needs
5. Department of Health and Environmental Control
6. Department of Mental Health
7. Department of Social Services
8. Department of Health and Human Services
9. Medical University of South Carolina
10. National Association of Social Workers, South Carolina Chapter
11. South Carolina Adult Day Services Association
12. South Carolina Association of Area Agencies on Aging
13. South Carolina Council on Aging Directors
14. South Carolina Association of Nonprofit Homes for the Aging
15. South Carolina Association of Residential Care Homes
16. South Carolina Health Care Association
17. South Carolina Home Care Association
18. South Carolina Hospital Association
19. South Carolina Medical Association
20. South Carolina Nurses Association
21. South Carolina Alzheimer's Disease Registry
22. South Carolina State University
23. University of South Carolina

The Advisory Council meets quarterly. Committees are appointed by the Chair and activated as needed.

Appendix A

ARCC Advisory Council Members

Mr. Jim Love
AARP

Ms. Beth Sulkowski
Alzheimer's Association - SC Chapter

Dr. Stephanie Davis
Clemson University

Ms. Mildred Lilley
Consumer/Caregiver

Dr. Jessica Broadway
Medical University of South Carolina

Ms. Sara English
National Association of Social Workers, South Carolina Chapter

Pending
South Carolina Adult Day Services Association

Pending
South Carolina Association of Area Agencies on Aging

Pending
South Carolina Association of Council on Aging Directors

Ms. Vickie Moody
LeadingAge South Carolina (formerly South Carolina Association of Non-Profit Homes for the Aging)

Pending
South Carolina Association of Residential Care Homes

Ms. Brenda Hyleman; Dr. Macie Smith
South Carolina Alzheimer's Disease Registry

Pending
South Carolina Department of Disabilities and Special Needs

Pending
South Carolina Department of Health and Environmental Control

Pending
South Carolina Department of Health and Human Services

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Dr. Miroslav Cuturic
South Carolina Department of Mental Health

Ms. Mildred Washington; Ms. Liz Crawley
South Carolina Department of Social Services

Pending
South Carolina Health Care Association

Pending
South Carolina Home Care and Hospice Association (formerly South Carolina Home Care Association)

Pending
South Carolina Hospital Association

Dr. Terry Dodge
South Carolina Medical Association

Ms. Marilynn Koerber
South Carolina Nurses Association

Pending
S.C. Silver Haired Legislature

Pending
South Carolina State University

Dr. Mindi Spencer
University of South Carolina

Pending
Dorn VA Medical Center

Ms. Patricia McCloud
At-Large

Staff: Anne Wolf, Elizabeth Ford

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Appendix B

Grants Awarded in July 2014 for FY 2014-2015

Alzheimer's Family Services of Greater Beaufort Respite Beaufort County	\$20,000
The ARK – St. Luke's Lutheran Education Dorchester County	\$20,000
Cura Respite Anderson County	\$20,000
Greenville Hospital System Education Greenville County	\$20,000
Memory Matters Education Beaufort County	\$20,000
The Oaks Adult Day Center Respite Orangeburg County	\$20,000
St. James South Santee Senior & Community Center Respite Charleston County	\$20,000
TOTAL GRANT AWARDS IN FISCAL YEAR 2014-2015	\$140,000²

² The remaining \$10,000 from the ARCC 2014-2015 fiscal year was carried forward to the 2015-2016 funds for future grantees.