Alzheimer's Resource Coordination Center

Annual Report

July 1, 2010 through June 30, 2011

Presented to the

South Carolina General Assembly
April, 2012

Lieutenant Governor's Office on Aging
Alzheimer's Resource Coordination Center
1301 Gervais Street, Suite 350
Columbia, South Carolina 29201
(803)734-9900

ARCC ANNUAL REPORT TO THE LEGISLATURE
Fiscal Year 2010-2011

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, 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 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 2010 SC Alzheimer's Disease Registry Annual Report identified 69,404 persons in South Carolina diagnosed with dementia as of January 1, 2008 through December 31, 2008, the most current period with available and comprehensive data. Approximately 274,195 persons care for these individuals (based on statistics provided by the Alzheimer's Association "2011 Alzheimer's Disease Facts and Figures"). The Registry predicts that the number of persons affected by Alzheimer's disease and other related dementias will double in the next 15 years and nearly triple in 25 years. 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 are the greatest. Therefore, this is an issue of growing concern and underscores the need for development of community-based services.

Approximately seventy percent of care for persons with Alzheimer's disease or related dementias is given in the home by family or friends. The physical, emotional, and financial demands on unpaid caregivers are huge, especially for those caring for a person with dementia. Families want to keep their loved one at home. However, the absence of supportive services which enable families to care for their loved one at home may lead to premature placement in an institutional setting, increasing the economic cost to the state and the psychological cost to the family caregiver.

The Alzheimer's Disease Registry reports that of the 69,404 persons currently living with Alzheimer's disease or a related disorder in South Carolina, 23,189 (33%) are known to reside in nursing homes and 43,135 (62%) reside in the community or an unknown location (3,080 or 5%). The 2011 MetLife Market Survey estimates the average nursing home cost for a semi-private room in South Carolina is $71,540 annually. Based on this figure the annual cost of nursing home care for persons with ADRD is $1.66 billion. Most persons with Alzheimer's disease are cared for at home by family members who provide care at great cost to their own physical, emotional, health and financial status. The Survey also provides an estimate for home care costs of $6205 annually in South Carolina. The Survey findings indicate that maintaining 43,135 people at home costs $268 million each year. The estimated total cost of nursing home and care in the home is

$1.93 billion annually. 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. If all Alzheimer's Registry patients resided in nursing homes, the cost would be approximately $4.97 billion each year. 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.

Part of the mission of the Alzheimer's Resource Coordination Center is to foster the development of a system of care that will provide families throughout the state with access to support and appropriate services. Whether those services are delivered in the home, the community or a residential setting, they should be responsive to the needs of the person with dementia and the primary caregiver. In furtherance of these goals, in June 2008 a concurrent resolution was passed in the General Assembly requesting the Lt. Governor's Office on Aging convene a Purple Ribbon Alzheimer's Task Force to study the current and future impact of Alzheimer's disease and related disorders so as to develop a state strategy to address this health issue. The report was due to the legislature by March 1, 2009 and has been submitted electronically to the legislature.

The Alzheimer's State Plan which was submitted to the legislature outlined twenty recommendations with a proposed time frame for implementation, ranging from 1-2 years up to 6-10 years. The Purple Ribbon Task Force comprised of a diverse membership, reached consensus on the recommendations along with the suggested agencies/entities to carry out the recommendations. Progress continues on implementation of recommendations. The ARCC Advisory Council strategized an approach for working to implement the recommendations. Priorities were discussed, along with opportunities for outreach and the role of the Council in these activities. Some of the work undertaken through the ARCC during this fiscal year has come to fruition. On Recommendation 3: Expand the scope of data included in the Alzheimer's Disease Registry, to include increased sources of data and result in greater capacity to identify gaps in services available; coordination and collaboration have resulted in one new data source being added for the Registry, with two additional resources in progress. Work on Recommendation 4: Utilize existing health data dissemination infrastructure to integrate information on Alzheimer's disease and related disorders has been successful for dissemination of ADRD materials in conjunction with outreach being done through the Office of Research and Statistics, South Carolina Health Integrated Data Services. The detailed list of recommendations may be found within the report located on the Lt. Governor's Office on Aging website, www.aging.sc.gov.

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. Educational programs target persons with Alzheimer's disease and their caregivers, 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 other resources.

The ARCC is the only entity in South Carolina that awards grants to start 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, offering technical assistance to encourage the sustainability of their programs.

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 2010-2011:

Number of Unduplicated Respite Participants	57
Hours of Respite Provided	33,850
Number of Support Group Meetings	75
Number of Educational Participants	4318
Number of Hours of Education	56

Nine grants were awarded in 2010-2011, comprised of seven respite programs and two educational 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 January 2011 and a grant procedures workshop for new grant

recipients in June 2011. Additionally, Alzheimer's information is made available "on-line" through the web site, 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 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 prevent our state from crisis.

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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.

II. ADVISORY COUNCIL

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

1. Alzheimer's Association Chapters
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

Pending
AARP

Ms. Cindy Alewine
Alzheimer's Association Upstate Chapter

Pending
Clemson University

Ms. Mildred Lilley
Consumer/Caregiver

Dr. Jacobo E. Mintzer
Medical University of South Carolina

Pending
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. F. Ann Shealy
South Carolina Association of Non-Profit Homes for the Aging

Ms. Karen S. Bowman
South Carolina Association of Residential Care Homes

Ms. Carol Cornman
South Carolina Alzheimer's Disease Registry

Dr. Graeme H. Johnson
South Carolina Department of Disabilities and Special Needs

Mr. Michael D. Byrd
South Carolina Department of Health and Environmental Control

Pending
South Carolina Department of Health and Human Services

Pending
South Carolina Department of Mental Health

Ms. Mildred Washington
South Carolina Department of Social Services

Pending
South Carolina Health Care Association

Mr. Jeffrey K. Neipp
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
South Carolina State University

Pending
University of South Carolina

Dr. Paul Switzer, III
Dorn VA Medical Center

Staff: Anne Wolf

Appendix B

Grants Awarded in July 2010 for FY 2010-2011

The Ark Education Dorchester County	$20,000
Alzheimer's Respite & Resource Respite Beaufort County	$10,000
BranCo Adult Daycare Center Respite Clarendon, Sumter, Williamsburg County	$10,000
Hopewell Senior Daycare, Inc. Respite Williamsburg County	$10,000
Respite Care Ministries Education Charleston County	$17,850
South Santee Senior and Community Center Respite Charleston County	$20,000
Strawberry Assistance Center Respite Berkeley County	$10,000
Adult Daycare 41 Respite Charleston County	$20,000
Sea Island Comprehensive Health Care Respite Charleston County	$10,000
TOTAL GRANT AWARDS IN FISCAL YEAR 2010-2011	**$127,850**