

ANNUAL REPORT TO THE LEGISLATURE JULY 1, 2022 - JUNE 30, 2023

### PRESENTED TO:

THE HONORABLE DANIEL B. "DANNY" VERDIN, III, CHAIRMAN SENATE MEDICAL AFFAIRS COMMITTEE

THE HONORABLE SYLLESTE H. DAVIS, CHAIRPERSON HOUSE MEDICAL, MILITARY, PUBLIC AND MUNICIPAL AFFAIRS COMMITTEE





To Governor Henry McMaster and members of the South Carolina General Assembly,

IThe South Carolina Department on Aging (SCDOA) has housed the state's Alzheimer's Resource Coordination Center and Council since 1994. For nearly three decades, our agency has worked alongside other state regional, and local providers to improve support for persons living with Alzheimer's and Related Dementias as well as their family caregivers. We have been privileged to have such impactful partners as South Carolina's Department of Health and Environmental Control (DHEC) to work alongside us in this mission.

The SCDOA's ARCC Council was the governing body to help inform recommendations for the Statewide Plan to Address Alzheimer's Disease and Related Dementias (ADRD). This five-year plan focuses on five major components: Education for Healthcare Providers and the General Public, Advocacy and Policymaking, Access and Connection to Care, Caregiver Support, and Improved access to coordination of and uses of ADRD data and resources. While all ARCC Council members were involved, other key stakeholders, such as the Alzheimer's Association, South Carolina Department of Social Services (SCDSS), South Carolina Department of Health and Human Services (DHHS), and many others, participated.

In 2022, the ARCC Advisory Council served as the representative coalition for the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Grant, awarded to SC DHEC. The BOLD grant helped to develop the South Carolina Statewide Plan to Address Alzheimer's Disease and Related Dementias and serves as a blueprint for care for persons living with dementia. The ARCC and its members continue to take steps to implement the objectives of the Statewide Plan to Address Alzheimer's Disease and related dementias, including through the work of the SC Department on Aging's Dementia Care Specialist who, since taking on the role in August 2022, has provided education and support to hundreds of persons impacted by ADRD, including those diagnosed, their families, caregivers, and service providers.

The ARCC Funds supported 13 grants in FY22-23, providing respite, education, and innovative programming to those impacted by Alzheimer's disease and related dementia across the state. Additionally, the ARCC has enabled South Carolina to move the needle forward on how we, as a state, address issues facing our caregivers by communicating, coordinating, and collaborating together. We must continue working alongside our stakeholders to invest in what we know will impact the quality of life for people with Alzheimer's disease.

We are grateful to our legislative champions at the State House and the collaboration of our state agencies and additional stakeholders on the ARCC to continue to make this issue a priority.

Respectfully,

Connie D. Munn, MSW

To Governor Henry McMaster and members of the South Carolina General Assembly,

In the United States today, nearly 7 million people are living with Alzheimer's disease. That number continues to grow as more people turn 65 every day. Without intervention, it is expected to increase to 13 million by 2050.

At the state level, we are in the midst of a dementia crisis. According to the South Carolina Alzheimer's Disease Registry, the most comprehensive population-based registry of its kind in the nation, over 122,699 South Carolinians are living with Alzheimer's or related dementia. By the numbers, the effects on our state are staggering:

- The Medicaid costs of caring for people with Alzheimer's in South Carolina (2020) were \$652 Million. Those costs are expected to rise 25.4% by 2025.
- South Carolina is the third largest neurology desert in the nation, facing a massive projected shortage of neurologists by 2025 for our dementia population.
- South Carolina only has 66 practicing geriatricians, physicians who specialize in serving our seniors' health needs. To meet demand by 2050 in the Palmetto State, we would need to see a 336.4% increase.
- An estimated 11.5% of our state population 65 years and older have Alzheimer's or related dementia.

In our state, 219,000 family caregivers provide over 361 million hours of unpaid care. Over 60% of these caregivers live with their chronic condition(s), and over 15% are in poor physical health themselves. That unpaid care provided by family members or friends is valued at over \$5.5 billion. We also know that 1 in 3 dementia caregivers in our state are "sandwich generation" caregivers — meaning that they care not only for someone with dementia but also for at least one child or grandchild.

As we learn more through research and prevention science, the South Carolina Department of Public Health has applied for and been awarded the Building Our Largest Dementia Infrastructure (BOLD) grant through the CDC. The priorities of the grant include risk reduction so we can help South Carolinians take steps to modify their risk factors and promote healthy behaviors that can reduce the risk of cognitive decline, possibly reduce the risk of dementia, and protect cognitive health. This, along with a focus on primary care providers to support early detection and early diagnosis, can help families have longer with their loved ones to prepare for care financially, mentally, and legally.

The Alzheimer's Resource Coordination Center (ARCC) is an essential foundation for this work. Established by South Carolina law (SECTION 44-36-310) in 1994, the mandate of the ARCC and its Advisory Council members 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."

The duties of ARCC Advisory Council members are specified by statute and appointed by the Governor, including a slate of several new appointees in 2021. Their responsibilities include attending quarterly Council meetings, participating in efforts to update South Carolina's Alzheimer's State Plan, recommending policy initiatives, advising the work of the SC Alzheimer's Registry, reviewing grants for Alzheimer's community education and caregiver support, and collaborating with Council members to advance services and supports for families facing Alzheimer's disease and related dementia in our state.

The work of the ARCC is overseen by our state Dementia Coordinator at the South Carolina Department on Aging. The work of the Division of Family Caregivers and Alzheimer's supplements it. The work of the Dementia Care Specialist is to provide dementia education and care consultations. These efforts have impacted hundreds across the state. Alzheimer's respite vouchers continue to be utilized by our caregivers as the demand for these vouchers and services continues to increase.

The ARCC has also been serving as a stakeholder group, helping to set in motion projects and programs to implement the objectives of the Alzheimer's state strategic plan. This plan, published in March 2023, provides a road map for the statewide work to support all families facing dementia. This plan also serves to fulfill the requirements of the Building Our Largest Dementia Infrastructure (BOLD) grant awarded to SC DHEC in September 2023 by the CDC. The next steps in the process, including strategic implementation planning and external stakeholder input, have begun in the spring of 2024 and will continue throughout the year.

The South Carolina Alzheimer's Association Chapter was awarded the Inaugural State Policy Achievement Award by the Alzheimer's Impact Movement in Washington, D.C. in April 2024. "It was an astounding year of progress in South Carolina," remarked Kenann Cassidy, Alzheimer's Association Area East Leader, as she bestowed the award upon South Carolina advocates. "In 2023, the state of South Carolina took tremendous steps to build an infrastructure that ensures a coordinated statewide response to Alzheimer's and all other dementia." South Carolina took absolutely vital steps to make a difference in all facing dementia and the risk of dementia to their families. The inaugural State Policy Achievement Award is coming home to the Palmetto State because of our many legislative supporters in the fight against Alzheimer's and all dementia. The collaboration brought together by the ARCC has made this progress possible.

We are grateful to our legislative champions at the State House and the collaboration of our state agencies and additional stakeholders on the ARCC to continue to make this issue a priority.

With all of this momentum through the ARCC, South Carolina is now poised to make a major impact on brain health, dementia support services, caregiving respite, and beyond, all thanks to the dedication and compassion of the SC General Assembly in investing in research, risk reduction, care and support and a collaborative, coordinated approach to address our dementia crisis statewide.

With your continued foresight and leadership, the SC General Assembly can help impacted families care for their loved ones at home longer, keep our caregivers healthier, and reduce the burden of the cost of care for taxpayers in South Carolina while supporting South Carolina as a research force in the field of dementia science.

Respectfully submitted,

. Dayor Wilson

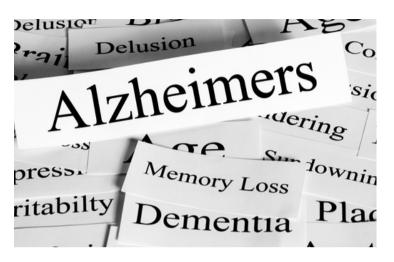
Chairperson, Alzheimer's Resource Coordination Center (ARCC)





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## I. 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 dementia (ADRD). their families careaivers through planning, education, coordination, advocacy, service system development, and communication.



The work of the ARCC is guided by an 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 those living with ADRD.



The 2023 Annual Report of the South Carolina Alzheimer's Disease Registry [1] reports that 122,699 individuals were living with Alzheimer's or Related Dementia (ADRD) in 2021. The Registry tracks information from January 1, 2020, through December 31, 2023, the most current years with available and comprehensive data.

According to the Alzheimer's Association's 2024 Alzheimer's Disease Facts and Figures, approximately 219,000 informal caregivers provided care for these individuals. The report projects a 51% increase in the number of persons affected by Alzheimer's disease and other related dementia between 2017 and 2050 [2].

Caregiving Information In the United States, more than 11 million Americans provided unpaid care in 2023 [2]. These caregivers provided an estimated 18.4 billion hours of unpaid care, valued at \$346.6 billion. The estimated value of care by family and unpaid caregivers in South Carolina alone was over \$5.5 billion in 2023 [2].

The physical, emotional, and financial demands on unpaid caregivers are huge, especially for those caring for a person with dementia. In South Carolina, 31% of caregivers suffer from depression, 60.6% have chronic health conditions, and 15.2% are in poor physical health [2]. Families want to keep their loved ones at home. However, the absence of supportive services that 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.



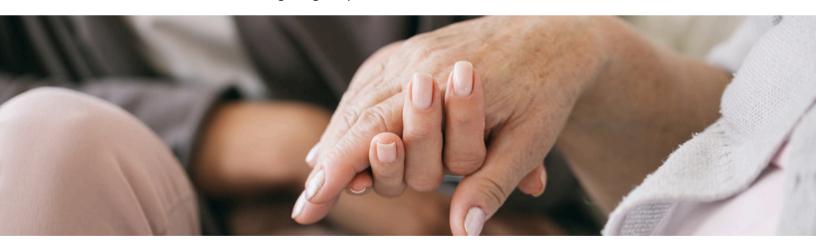
The Alzheimer's Disease Registry reports that of the 122,699 individuals currently living with ADRD in South Carolina, 70% are known to reside in the community, 23% reside in nursing facilities, and another 7% live in unknown locations [1]. The 2023 Genworth "Cost of Care" Survey estimates the average nursing home cost for a private room in South Carolina is \$112,420 annually, while the median home health aide costs \$73,216 annually [3].

Most persons with ADRD are cared for at home by family members who provide care at a great cost to their own physical and emotional health as well as their financial status. Families or informal caregivers also pay for a considerable portion of this cost.

In 2023, the Medicaid cost of caring for people with ADRD in South Carolina was \$652 million [2]. This number is projected to increase by 25.4% to \$818 million by 2025. In 2023, Medicare spent \$29,657 per capita on people living with dementia in South Carolina. South Carolina must find ways to assist and support caregivers in maintaining their loved ones and friends at home as long as possible to avoid or delay institutionalization

Caregivers of persons with ADRD in South Carolina often identify their top needs as:

- Caregiver support, in the form of emotional support, financial support, family support, and support groups;
- Information and resources on the disease; and
- Respite services that will allow caregivers to take a short break from their 24/7 caregiving responsibilities.



Experience has shown that support for caregivers can promote a higher quality of life for the person with ADRD and the family. By relieving some of the burdens, even on a temporary short-term basis, supportive services can enable families to continue to care for the person with ADRD at home. Supportive services such as adult day services, group respite care, in-home respite, caregiver education, and counseling can help to prevent or delay institutionalization at a fraction of the cost of institutional care.

[3] Genworth Financial. (2023). Genworth Cost of Care Survey. Retrieved from: https://www.genworth.com/aging-and-vou/finances/cost-of-care

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Beginning in 1995, the Legislature has addressed this need by allocating 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 dementias. Since its inception, 360 grants have been awarded to communities for dementia-specific respite, adult day programs, education programs, and innovative programs that support persons living with dementia, their families, caregivers, and communities. These grants have also been used to provide services to the medical community, colleges and universities, first responders, and the general public. ARCC grants have provided respite care services to more than 7,382 individuals living with ADRD, education services to more than 68,843 participants, and supported the implementation of 11 innovative programs.

The ARCC is the only government entity in South Carolina that awards grants to start dementia-specific respite, education, and innovative programs in the community. 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.

Alzheimer's disease is one of the costliest and most uninsured health risks South Carolina families are likely to face. The U.S. Census Bureau projects that in 2030, South Carolina will be home to 1.1 million people over the age of 65, potentially propelling South Carolina to a ranking of 15th in the nation for the highest percentage of adult residents 65 and older.

Increasing age is a leading risk factor for Alzheimer's disease, and South Carolina's rapidly growing older population presents a challenge to families, communities, and those who plan and deliver services for the state. 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 dementia with programs and services in place, rather than trying to handle the epidemic after it has started.

# SUPPORTIVE SERVICES PROVIDED BY FIRST AND SECOND YEAR ARCC GRANTEES

2022-2023

Supportive Services Provided by ARCC Grantees in 2022- 2023:	
Number of Unduplicated Respite Participants	13
Hours of Respite Provided	1,778
Number of Support Group Meetings	47
Number of Educational Participants	3,171
Number of Hours of Education	1,789
Number of Innovative Programs	5

Thirteen grants were awarded in 2022–2023, comprised of four respite programs, two education programs, three innovative programs, one innovative & education program, two respite and education programs, and one respite, innovative, & education program. All ARCC grant awards are equally matched with community funding and resources. A plan is required for the continuation of the program after grant funding is discontinued. Standardized reporting for all grant programs is required to ensure fidelity to the objectives outlined in the grant application.

As part of the grant process, the ARCC sponsored a pre-proposal workshop for prospective grantees in February 2022 and a grant procedures workshop for new grant recipients in June 2022. Additionally, ARCC grant information was 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. Substantial cost savings are 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 persons living with Alzheimer's and related dementias. If our leadership fails to act, taxpayers will be forced to foot the bill for the huge cost differences. We thank the South Carolina Legislature for its continued support in providing relief, respite, and education to South Carolinians with Alzheimer's disease and related dementias and their caregivers. However, further investigation into the the savings that our state will see through the promotion of home and community-based services is warranted.

Due to the unprecedented growth of the population of older adults in our state, it is vital to our state's welfare, citizens, and economy that our leadership study these potential savings that could very well avert a crisis in our state.



#### A. Enabling Legislation

The Alzheimer's Resource Coordination Center was created in the Division on Aging Act of the South Carolina Legislature effective April 20, 1994, and is now housed in the South Carolina Department on Aging. 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 Chairman of the Medical Affairs Committee of the Senate and the Chairman of the Medical, Military, Public, and Municipal Affairs Committee of the House of Representatives.
- (8) Facilitate coordination and integration of educational initiatives for healthcare providers on the importance and value of early detection and timely diagnosis of cognitive impairment, validated cognitive assessment tools, and increasing understanding and awareness of early warning signs of Alzheimer's disease and other types of dementia and how to reduce the risk of cognitive decline.
- (9) Convene the advisory council to update the statewide plan to address Alzheimer's disease and related dementias.
- (10) When updating the statewide plan, the advisory council must solicit input from the Department of Health and Environmental Control, the Department of Health and Human Services, and the Department of Social Services to ensure the formulation of a comprehensive statewide plan that meets the needs of the State.
- (11) Submit an annual report to the Governor and the General Assembly by September 30th concerning progress toward fulfilling the statewide plan.

#### **C. Community Grants**

Beginning in 1995, the state legislature has allocated \$150,000 each year to the ARCC to provide grants to community organizations that support those living with ADRD, their families, caregivers, and communities. These grants are awarded on a two-year basis and are used to help with the development or expansion of respite care, education, or innovative programming relating to those living with ADRD and their families. The ARCC Advisory Council provides recommendations on priority needs and criteria for selecting grant recipients. Grant recipients must provide matching funds or an in-kind contribution equal to the amount of funds awarded in the grant.



# III. ADVISORY COUNCIL

According to the SC Code of Laws Section 44-36-330, the ARCC must be supported by an advisory council appointed by the Governor including, but not limited to, representatives of:

- 1. Alzheimer's Association, South Carolina Chapter
- 2. American Association of Retired Persons (AARP) South Carolina Chapter
- 3. Clemson University
- 4. Department of Disabilities and Special Needs
- 5. Department of Health and Environmental Control
- 6. Department of Health and Human Services
- 7. Department of Mental Health
- 8. Department of Social Services
- 9. Medical University of South Carolina
- 10. National Association of Social Workers, South Carolina Chapter
- 11. South Carolina Adult Day Care Association (now known as the 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 (now known as LeadingAge SC)
- 15. South Carolina Association of Residential Care Homes (now known as South Carolina Assisted Living Association)
- 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

Represented Entities Not Listed in State Legislature:

- 24. Consumer/Family Caregiver
- 25. Consumer/Family Caregiver
- 26 Silver Haired Legislature
- 27. Veteran's Health Administration

The Advisory Council meets quarterly and Sub-Committees meet as needed.

IV. Alzheimer's Disease and Related Dementia
State Plan

During the 2022-2023 fiscal year, the ARCC Advisory Council served as the representative coalition for the South Carolina Department of Health and Environmental Control's (DHEC) Division of Injury and Substance Abuse Prevention's 2018 Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Grant. The BOLD grant aims to increase early detection and diagnosis, reduce risks, prevent avoidable hospitalizations, and support dementia caregiving. Work on the BOLD grant helped to develop the South Carolina Statewide Plan to Address Alzheimer's Disease and Related Dementias.

The plan focuses on five principal goals, each associated with a list of actionable items:

2023 to 2028

South Carolina Statewide Plan to Address Alzheimer's Disease & Related Dementias (ADRD)



- Improve knowledge, understanding, and awareness of Alzheimer's disease and related dementia by educating and empowering South Carolinians, including every person engaged in the continuum of care.
- Support policy and advocacy efforts that improve the health and well-being of all people in South Carolina.
- Improve the quality of dementia care and ensure all people in South Carolina can access the resources, healthcare, and support they need to reduce the risk and all other issues related to ADRD.
- Improve, expand, and develop multidimensional support and health promotion programs for professional and family caregivers and care partners.
- Improve access to, coordination, and use of ADRD data and resources statewide.

The statewide plan serves as a blueprint for care for persons living with ADRD in South Carolina from 2023-2028. Section 44-36-320 of the South Carolina Code of Laws mandates that the ARCC must provide an annual report to the State Legislature each September outlining the State Plan's progress. Additionally, Section 44-36-330 states that "the advisory council shall maintain and update a statewide plan to address Alzheimer's disease and related dementias. The plan must be updated every five years."

### **Dementia Care Specialist**

Education about dementia and valuable resources is a vital component of the Statewide Plan to Address Alzheimer's Disease and Related Dementia. The South Carolina Department on Aging has recognized this need and began planning a role for community education and care consultations.

In August of 2022, the South Carolina Department on Aging hired its first Dementia Care Specialist to help educate the public about dementia and provide needed support to families navigating a dementia diagnosis. Since that time, our Dementia Care Specialist has developed an educational webinar, Dementia 101: The Basics, reaching 449 participants. Additionally, she saw a need for further community education and developed Dementia 201: Positive Interactions\*\*, which in its first month reached 49 participants.

Various community presentations on dementia have been conducted, reaching 688 individuals. Our Dementia Care Specialist has assisted 189 families in navigating a dementia diagnosis to provide individualized care consultations.

# Number of Individuals to Receive Services from the South Carolina Department on Aging Dementia Care Specialist

Dementia 101: The Basics	449
Dementia 201: Positive Interactions	49
Community Presentations	688
Care Consultation	189

<sup>\*\*</sup> Dementia 201: Positive Interactions was first presented in March 2024

### Appendix A - ARCC Advisory Council Members for Fiscal Year 2022-2023

Alzheimer's Association-SC Chapter

Ms. Taylor Wilson (Chair)

Mr. Joseph Meyers

SC Association of Area Agencies on Aging

Ms. Janae Stowe

AARP South Carolina Council on Aging Directors

Mr. Andrew Boozer

Clemson University LeadingAge, SC

Dr. Nicole Davis Ms. Vicky Moody\*, Ms. Kassie South

Coastal Carolina University SC Association of Residential Care Homes

Dr. Cynthia Port Ms. Denise Kish (Vice-Chair)

Consumer/Caregiver 1 South Carolina Health Care Association

Ms. Angela Sanders\* Ms. Melissa Gilliam

Consumer/Caregiver 2 South Carolina Home Care Association

Dr. Scott Habakus Ms. Mary Peck

Department of Disabilities and Special Needs South Carolina Hospital Association

Mr. Robert McBurney PENDING

Department of Health and Environmental Control South Carolina Medial Association

Ms. Emma Kennedy PENDING

Department of Health and Human Services South Carolina Nurses Association

Ms. Margaret Alewine PENDING

Department of Mental Health South Carolina Silver-Haired Legislature

Dr. Miroslav Cuturic Ms. Rebecca Smith

Department of Social Services South Carolina State University

Ms. Kelly Cordell Dr. Miriam Evans

Medical University of South Carolina SC Alzheimer's Disease Registry

Dr. Steve Carroll Dr. Maggi Miller

National Association of Social Workers, SC Chapter University of South Carolina

Ms. Sara English Ms. Megan Byers (Secretary)

South Carolina Adult Day Association Veterans Health Administration

PENDING Dr. Jessica Broadway

Staff: Ms. Jennifer Brewton, Ms. Sheila Lewis\*

<sup>\*</sup>Denotes that individual is no longer with the ARCC/Advisory Council

### Appendix B - Grants Awarded in Fiscal Year 2022-2023

Alzheimer's Family Services of Greater Beaufort Respite	\$20,000
Beaufort County	
ARK of SC, The	\$10,000
Education	
Dorchester County	
Golden Corner Respite	\$10,000
Respite	
Dorchester County	
Leeza's Care Connection +	\$30,000
Education and Innovative	
Lexington & Richland Counties	
Lexington County Sheriff's Department	\$20,000
Education & Innovative	
Lexington County	
MapHabit, Inc	\$19,895
Innovative	
Aiken County  Midlands Community Development Corporation ++	\$30,000
Education & Innovative	
Richland County  Mother DeVeaux Adult Day Care +	\$30,000
Respite & Education	
Richland County	
Newberry County Council on Aging	\$20,000
Respite	
Newberry County	
Respite Care Charleston	\$20,000
Respite	
Charleston County	
SC Christian Action Council	\$20,000
Education	
Richland County	
St. James South Santee Senior and Community Center	\$20,000
Respite	
Charleston County	
Straight Road International	\$14,500
Education	
Richland County	
TOTAL GRANT AWARDS	\$264,395

<sup>+</sup>Award includes funds rolled over from the previous fiscal year

<sup>++</sup>Midlands Community Development Corporation was unable to get their program started in the 2022-2023 fiscal year and returned their funds

South Carolina Department on Aging Alzheimer's Resource Coordination Center

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