CHAPTER 36

Alzheimer's Disease and Related Disorders

Article 1

Alzheimer's Disease Registry

**SECTION 44-36-10. Establishment of Registry; purpose and functions; sources of data.**

 (A) There is established within the University of South Carolina School of Public Health the Alzheimer's Disease Registry to provide a central information data base on individuals with Alzheimer's disease or related disorders to assist in the development of public policy and planning.

 (B) The functions of the registry include, but are not limited to:

 (1) collecting data to evaluate the incidence, prevalence, and causes of Alzheimer's disease and related disorders in South Carolina;

 (2) providing information for policy planning purposes; and

 (3) providing nonidentifying data to support research on Alzheimer's disease and related disorders.

 (C) In gathering data the registry shall rely upon, to the extent possible, data from existing sources; however, the registry may contact families and physicians of persons reported to the registry for the purpose of gathering additional data and providing information on available public and private resources. The registry is authorized to conduct follow-back studies, prospective studies of the progression and treatment of Alzheimer's disease and related disorders, and research on caregiving for individuals with Alzheimer's disease or a related disorder, on services used by individuals with Alzheimer's disease or a related disorder, and on causes of Alzheimer's disease and related disorders that examine risks associated with area of residence. Patient contact following data received from the Revenue and Fiscal Affairs Office must be done in accordance with regulations approved by the South Carolina Data Oversight Council and promulgated by the Revenue and Fiscal Affairs Office. Caregivers must provide informed consent to participate in research on caregiving.

HISTORY: 1990 Act No. 532, § 1; 1995 Act No. 75, § 1; 2009 Act No. 31, § 1, eff June 2, 2009.

**SECTION 44-36-20. Advisory committee; membership; duties; prohibition against compensation.**

 (A) The School of Public Health shall appoint an advisory committee to assist in maintaining this registry which must include, but is not limited to, a representative of:

 (1) South Carolina Alzheimer's Association chapters;

 (2) American Association of Retired Persons, South Carolina Chapters;

 (3) Clemson University;

 (4) Office of Intellectual and Developmental Disabilities;

 (5) Department of Health and Environmental Control;

 (6) Office 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 Care Association;

 (12) South Carolina Association of Area Agencies on Aging;

 (13) South Carolina Association of 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) Alzheimer's Disease and Related Disorders Resource Coordination Center of the Department on Aging;

 (22) University of South Carolina;

 (23) South Carolina State University.

 (B) The advisory committee shall assist the registry in:

 (1) defining the population to be included in the registry including, but not limited to, establishing criteria for identifying patient subjects;

 (2) developing procedures and forms for collecting, recording, analyzing, and disseminating data;

 (3) developing protocols and procedures to be disseminated to and used by health care providers in identifying subjects for the registry;

 (4) developing procedures for approving research projects or participation in research projects.

 (C) Members of the advisory committee are not entitled to mileage, per diem, subsistence, or any other form of compensation.

HISTORY: 1990 Act No. 532, § 1; 1993 Act No. 181, § 1101; 1995 Act No. 75, § 1; 2018 Act No. 261 (S.107), Pt I, § 14, eff January 1, 2019.

**SECTION 44-36-30. Confidentiality; release of identifying information upon consent.**

 (A) The School of Public Health and all persons to whom data is released shall keep all patient information confidential. No publication of information, biomedical research, or medical data may be made which identifies the patients. For purposes of maintaining this registry, the School of Public Health may access appropriate confidential data reported to the Revenue and Fiscal Affairs Office in accordance with Section 44-6-170.

 (B) Except for use in collecting data on deaths from the Bureau of Vital Statistics, Department of Health and Environmental Control, no identifying information collected or maintained by the registry may be released unless consent is obtained from the subject or the subject's legal representative.

HISTORY: 1990 Act No. 532, § 1; 1995 Act No. 75, § 1.

**SECTION 44-36-40. Immunity from liability for divulging confidential information.**

 Neither the registry or the School of Public Health nor a person, medical facility, or other organization providing or releasing information in accordance with this article may be held liable in a civil or criminal action for divulging confidential information unless the person or organization acted in bad faith or with malicious purpose.

HISTORY: 1995 Act No. 75, § 1.

**SECTION 44-36-50. Annual report requirement.**

 The registry shall submit an annual report to the Alzheimer's Disease and Related Disorders Resource Coordination Center of the Department on Aging, the Department of Health and Environmental Control, and the Revenue and Fiscal Affairs Office.

HISTORY: 1995 Act No. 75, § 1; 2018 Act No. 261 (S.107), Pt I, § 15, eff January 1, 2019.

Article 3

Alzheimer's Disease and Related Disorders Resource Coordination Center

**SECTION 44-36-310. Alzheimer's Disease and Related Disorders Resource Coordination Center created; purpose.**

 In the Department on Aging, there is created the Alzheimer's Disease and Related Disorders Resource Coordination Center 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.

HISTORY: 1994 Act No. 326, § 1; 2012 Act No. 218, § 1, eff June 7, 2012; 2018 Act No. 261 (S.107), Pt I, § 16, eff January 1, 2019.

**SECTION 44-36-320. Duties of center.**

 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 in addition to publishing the report on the Governor's website;

 (8) facilitate the coordination and integration of educational initiatives for health care 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; and

 (11) submit an annual report to the Governor and the General Assembly by September thirtieth concerning progress toward fulfilling the statewide plan.

HISTORY: 1994 Act No. 326, § 1; 2012 Act No. 218, § 1, eff June 7, 2012; 2018 Act No. 261 (S.107), Pt I, § 17, eff January 1, 2019; 2019 Act No. 20 (S.205), § 1, eff April 26, 2019; 2023 Act No. 62 (S.569), § 1, eff May 19, 2023.

**SECTION 44-36-330. Advisory council; membership; compensation of members.**

 (A) The Alzheimer's Disease and Related Disorders Resource Coordination Center must be supported by an advisory council appointed by the Governor including, but not limited to, representatives of:

 (1) Alzheimer's Association Chapters;

 (2) American Association of Retired Persons;

 (3) Clemson University;

 (4) Office of Intellectual and Developmental Disabilities;

 (5) Department of Health and Environmental Control;

 (6) Office 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 Care Association;

 (12) South Carolina Association of Area Agencies on Aging;

 (13) South Carolina Association of 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) Statewide Alzheimer's Disease and Related Disorders Registry;

 (22) University of South Carolina;

 (23) South Carolina State University.

 (B) Members of the advisory council are not entitled to mileage, per diem, subsistence, or any other form of compensation.

 (C) 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.

HISTORY: 1994 Act No. 326, § 1; 1994 Act No. 326, § 3; 2012 Act No. 218, § 1, eff June 7, 2012; 2018 Act No. 261 (S.107), Pt I, § 18, eff January 1, 2019; 2023 Act No. 62 (S.569), § 2, eff May 19, 2023.

Article 5

Special Care Disclosure

**SECTION 44-36-510. Short Title.**

 This article may be cited as the "Alzheimer's Special Care Disclosure Act"

HISTORY: 1996 Act No. 336, § 2.

**SECTION 44-36-520. Information respecting form of Alzheimer's care or treatment provided.**

 A nursing home, community residential care facility, or day care facility for adults licensed by the Department of Health and Environmental Control which offers to provide or provides an Alzheimer's special care unit or program must include in its policies and procedures and disclose to the responsible party seeking a placement within the Alzheimer's special care unit or program, the form of care or treatment provided that distinguishes it as being especially applicable to or suitable for persons with Alzheimer's disease. The information that distinguishes the form of care or treatment shall include criteria for admission, transfer, and discharge; care planning; staffing patterns; staff training; physical environment; resident and participant activities; family role in care; and unique costs to the resident or participant associated with specialized service delivery.

HISTORY: 1996 Act No. 336, § 2.