

AN ACT concerning public health.

**Be it enacted by the People of the State of Illinois,
represented in the General Assembly:**

Section 5. The Alzheimer's Disease Assistance Act is amended by changing Sections 2, 3, 4, 5, 6, and 7 as follows:

(410 ILCS 405/2) (from Ch. 111 1/2, par. 6952)

Sec. 2. Policy declaration. The General Assembly finds that dementia is a general term for cognitive decline caused by various diseases and conditions that result in damaged brain cells or connections between brain cells. Alzheimer's disease is the most common type of dementia, caused by physical changes in the brain and accounting for 60% to 80% of cases. There are many other causes of dementia, known here as related disorders. Today Alzheimer's disease affects ~~Alzheimer's disease and related disorders are devastating health conditions which destroy certain vital cells of the brain and which affect an estimated 5,400,000 4,500,000 Americans;.~~ This means that approximately 210,000 ~~200,000~~ Illinois citizens have Alzheimer's disease ~~are victims~~. The General Assembly also recognizes that the incidence of Alzheimer's disease is rising and expected to reach 240,000 in Illinois by 2025. The General Assembly finds that Medicaid costs for individuals with Alzheimer's disease are 9 times higher than the costs for a

person without Alzheimer's disease in the same age group and that 71% of all Illinois nursing home residents have some degree of cognitive impairment, with more than half of that group having moderate to severe cognitive decline ~~finds that 50% of all nursing home admissions in the State may be attributable to the Alzheimer's disease and related disorders and that these conditions are the fourth leading cause of death among the elderly.~~

The General Assembly also finds that Alzheimer's is not a normal part of aging, although the greatest known risk factor is increasing age, and the majority of people with Alzheimer's are 65 and older. But Alzheimer's is not just a disease of old age. Up to 5% of people with the disease have early-onset Alzheimer's (also known as younger-onset), which often appears when someone is in their forties or fifties. It is the opinion of the General Assembly that Alzheimer's disease and related disorders cause serious financial, social, and emotional hardships on persons with Alzheimer's disease or related disorders ~~the victims~~ and their families of such a major consequence that it is essential for the State to develop and implement policies, plans, programs and services to alleviate such hardships.

The General Assembly recognizes that there is no known cause or cure of Alzheimer's disease at this time, and that it can progress over an extended period of time and to such a degree that a person with Alzheimer's disease dies from

Alzheimer's disease. The General Assembly recognizes that Alzheimer's disease is the sixth leading cause of death across all ages in the United States and the fifth leading cause of death for those aged 65 or older ~~the victim's deteriorated condition makes him or her susceptible to other medical disorders that generally prove fatal.~~ It is the intent of the General Assembly, through implementation of this Act, to establish a program for the conduct of research regarding the cause, cure and treatment of Alzheimer's disease and related disorders; and, through the establishment of Regional Alzheimer's Disease Assistance Centers and a comprehensive, Statewide system of regional and community-based services, to provide for the identification, evaluation, diagnosis, referral and treatment of individuals with Alzheimer's disease or related disorders. It is also the intent of the General Assembly to provide adequate and appropriate State policy and regulations to ensure that Illinois persons with Alzheimer's disease and related disorders are able to maintain their quality of life and their dignity as they progress through the course of the disease ~~victims of such health problems.~~

(Source: P.A. 93-929, eff. 8-12-04.)

(410 ILCS 405/3) (from Ch. 111 1/2, par. 6953)

Sec. 3. Definitions. As used in this Act:

(a) "Alzheimer's disease ~~and related disorders~~" or "Alzheimer's" or "AD" means the most common form of dementia

that causes problems with memory, thinking, and behavior. Symptoms usually develop slowly and get worse over time, becoming severe enough to interfere with daily tasks. Symptoms include a decline in memory and the loss of function in at least one other cognitive ability, such as the ability to generate coherent speech or understand written or spoken language; the ability to recognize or identify objects; the ability to execute motor activities; or the ability to think abstractly ~~a health condition resulting from significant destruction of brain tissue with resultant loss of brain function, including, but not limited to, progressive, degenerative and dementing illnesses including presenile and senile dementias, including Alzheimer's disease and other related disorders.~~

(a-5) "Dementia" means cognitive decline, including a loss of memory and other mental abilities severe enough to interfere with daily life.

(a-10) "Related disorders" or "related dementias" means any other form of dementia that is not caused by Alzheimer's disease.

(a-15) "Dementia-capable State" means that the State of Illinois and its long-term care services, community-based services, and dementia support systems have:

(1) the ability to identify people with dementia and their caregivers;

(2) information, referral, and service coordination

systems that provide person-centered services to people with dementia and their caregivers;

(3) eligibility criteria for public programs that are equitable for people with dementia;

(4) coverage of services that people with dementia and their caregivers are likely to use;

(5) a professional caregiving workforce that knows about Alzheimer's disease and other dementias and how to serve that population and their caregivers; and

(6) quality assurance systems that take into account the unique needs of people with dementia and their caregivers.

(b) "Regional Alzheimer's Disease Assistance Center" or "Regional ADA Center" means any postsecondary higher educational institution having a medical school in affiliation with a medical center and having a National Institutes of Health and National Institutes on Aging sponsored Alzheimer's Disease Core Center. Any Regional ADA Center which was designated as having a National Alzheimer's Disease Core Center but no longer carries such designation shall continue to serve as a Regional ADA Center.

(c) "Primary Alzheimer's provider" means a licensed hospital, a medical center under the supervision of a physician licensed to practice medicine in all of its branches, or a medical center that provides medical consultation, evaluation, referral and treatment to persons who may be or who have been

diagnosed as individuals with ~~victims of~~ Alzheimer's disease or related disorders pursuant to policies, standards, criteria and procedures adopted under an affiliation agreement with a Regional ADA Center under this Act.

(d) "Alzheimer's disease assistance network" or "ADA network" means the various health, mental health and social services agencies that provide referral, treatment and support services under standards and plans adopted and implemented in conjunction with a Regional ADA Center.

(e) "ADA Advisory Committee" or "Advisory Committee" or "Committee" means the Alzheimer's Disease Advisory Committee created under Section 6 of this Act.

(f) "Department" means the Illinois Department of Public Health.

(Source: P.A. 90-404, eff. 8-15-97.)

(410 ILCS 405/4) (from Ch. 111 1/2, par. 6954)

Sec. 4. Development of standards for a service network and designation of regional centers and primary providers. By January 1, 1987, the Department, in consultation with the Advisory Committee, shall develop standards for the conduct of research and for the identification, evaluation, diagnosis, referral and treatment of individuals with ~~victims of~~ Alzheimer's disease and related disorders and their families through the ADA network of designated regional centers and other providers of service under this Act. Such standards shall

include all of the following:

(a) A description of the specific populations and geographic areas to be served through ADA networks that may be established under this Act.

(b) Standards, criteria and procedures for designation of Regional ADA Centers, which ensure the provision of quality care to a broad segment of the population through on-site facilities and services and through a network of primary Alzheimer's providers and other providers of service that may be available within the service area defined by the Department. At least 2 Regional ADA Centers shall be conveniently located to serve the Chicago metropolitan area and at least one Regional ADA Center shall be conveniently located to serve the balance of the State. The Regional ADA Centers shall provide at least the following:

(1) comprehensive diagnosis and treatment facilities and services which have (i) professional medical staff specially-trained in geriatric medicine, neurology, psychiatry and pharmacology, and the detection, diagnosis and treatment of Alzheimer's disease and related disorders, (ii) sufficient support staff who are trained as caregivers to individuals with ~~victims of~~ Alzheimer's disease and related disorders, (iii) appropriate and adequate equipment necessary for diagnosis and treatment, and (iv) ~~transportation~~

~~services necessary for outreach to the service area defined by the Department and for assuring access of patients to available services, and (v) such other support services, staff and equipment as may be required;~~

(2) consultation and referral services for individuals with AD ~~victims~~ and their families or demonstrated instances of referral to consultation and referral services provided by organizations and agencies specializing in Alzheimer's disease and related disorders for those affected to ensure informed consent to treatment and to assist them in obtaining necessary assistance and support services through primary Alzheimer's providers and various private and public agencies that may otherwise be available to provide services under this Act;

(3) research programs and facilities to assist faculty and students in discovering the cause of and the diagnosis, cure and treatment for Alzheimer's disease and related disorders;

(4) training, consultation and continuing education for caregivers or demonstrated instances of referral to training, consultation, and continuing education provided by organizations and agencies specializing in Alzheimer's disease and related disorders for those affected, including families of

those who are affected by Alzheimer's disease and related disorders;

(5) centralized data collection, processing and storage that will serve as a clearinghouse of information to assist individuals with AD ~~victims~~, families and ADA Resources, and to facilitate research; and

(6) programs of scientific and medical research in relation to Alzheimer's disease and related disorders that are designed and conducted in a manner that may enable such center to qualify for Federal financial participation in the cost of such programs.

(c) Procedures for recording and reporting research and treatment results by primary Alzheimer's providers and other affiliated providers of service that are within the ADA network to the Regional ADA Center and to the Department.

(d) Policies, procedures and minimum standards and criteria to be included in affiliation agreements between primary Alzheimer's providers and the Regional ADA Center in the conduct of any research and in the diagnosis, referral and treatment of individuals with ~~victims~~ of Alzheimer's disease and related disorders and their families.

(e) Policies, procedures, standards and criteria, including medical and financial eligibility factors,

governing admission to and utilization of the programs, facilities and services available through the ADA network by persons who may be or who have been diagnosed as having ~~victims of~~ Alzheimer's disease or a ~~and~~ related disorder ~~disorders~~, including forms and procedures for obtaining necessary patient consents to participation in research, and in the reporting and processing of appropriate information in a patient's medical records in relation to consultations, referrals and treatments by the various providers of service within the ADA network.

(Source: P.A. 90-404, eff. 8-15-97; 91-357, eff. 7-29-99.)

(410 ILCS 405/5) (from Ch. 111 1/2, par. 6955)

Sec. 5. State ADA Plan. By January 1, 2014 ~~1987~~, and every 3 years thereafter, the Department shall prepare a State Alzheimer's Disease Assistance Plan in consultation with the Advisory Committee to guide research, diagnosis, referral and treatment services within each service area described by the Department. To ensure meaningful input by stakeholders into the plan, the Department or members of the General Assembly or other interested parties may hold public hearings at locations throughout the State for input by consumers and providers of care. The Department or members of the General Assembly or other interested parties may also utilize technological means or work with advocacy organizations that have technological capability, such as Webcasts or online surveys, to gather

feedback on recommendations from persons and families affected by Alzheimer's disease and the general public. State agencies with programs serving the population impacted by Alzheimer's may also present testimony at one of the State hearings to specify how they are meeting the needs of people with Alzheimer's. Various stakeholders, including related consumer organizations or advocacy organizations as well as individuals with Alzheimer's disease or a related disorder and caregivers of such individuals, may also be invited to provide public comment. The results of any public hearings held pursuant to this Section shall be presented to the Department in a format as determined by the Department to be included in the State Alzheimer's Disease Assistance Plan.

The plan shall incorporate any testimony that may be offered on the following topics:

(1) An assessment of the current and future impact of Alzheimer's disease on Illinois residents.

(2) An examination of the existing industries, services, and resources addressing the needs of persons with Alzheimer's, their families, and caregivers.

(3) The development of a strategy to mobilize a State response to this public health crisis.

(4) Trends in State Alzheimer's population and needs, including the changing population with dementia, including, but not limited to, the use of State surveillance data of persons with Alzheimer's disease for

purposes of having proper estimates of the number of persons in the State with Alzheimer's disease.

(5) The current economic impact of Alzheimer's disease and related disorders for the State, including the cost of direct and indirect care paid by Medicaid, other federal-State funded programs, the estimated direct and indirect costs of family caregiving, and the cost of Alzheimer's disease to businesses in Illinois.

(6) Existing services, resources, and capacity, including, but not limited to, the:

(a) type, cost, and availability of dementia services in this State;

(b) dementia-specific training requirements for paid professionals at any level and in any provider setting (institutional or home or community based) engaged in the care of persons with dementia;

(c) quality care measures instituted in this State for long-term care facilities; assisted living facilities; supportive living facilities; or any other residential program available for the care of persons with dementia;

(d) capacity of public safety and law enforcement to respond to persons with Alzheimer's;

(e) availability of and amount spent by the State on home and community-based resources for persons with Alzheimer's and related disorders and the availability

of State-supported respite care to assist families;

(f) inventory of all residential options for individuals with dementia in this State, including, but not limited to, long-term special care units for people with dementia, assisted living units for dementia, and supportive living units for dementia;

(g) inventory of geriatric-psychiatric units for persons with behavior disorders associated with Alzheimer's and related disorders;

(h) specific efforts of State agencies directed towards persons with Alzheimer's disease and related disorders and the agencies' estimation of resources that will be needed to meet an increased demand; and

(i) level of State support of Alzheimer's research through Illinois universities or other institutions and the results of such investments reflected both in research outcomes and subsequent federal investment in research in Illinois.

(7) Recommended changes or additions to State policies, including, but not limited to, directions for the provision of clear and coordinated services and supports to persons and families living with Alzheimer's and related disorders and strategies to address any identified gaps in services. ~~Such plan shall indicate any research programs being conducted and the status, results, costs and funding sources of such programs.~~

The plan shall also indicate the number of persons served, the extent of services provided, and the resources required for the delivery of services through the ADA networks established under this Act. Such plan shall identify and describe the duties and accomplishments of each Regional ADA Center, the primary Alzheimer's providers and other various providers of service within the ADA network of the described service area. The Department shall consult with and take into consideration the plans of local and State comprehensive health planning agencies recognized under the Comprehensive Health Planning Act, as well as recommendations regarding Alzheimer's disease and related disorders that may be included in the State Health Improvement Plan.

(Source: P.A. 84-378; 84-513.)

(410 ILCS 405/6) (from Ch. 111 1/2, par. 6956)

Sec. 6. ADA Advisory Committee. There is created the Alzheimer's Disease Advisory Committee consisting of 23 ~~21~~ voting members appointed by the Director of the Department, as well as 5 nonvoting members as hereinafter provided in this Section. The Director or his designee shall serve as one of the 23 ~~21~~ voting members and as the Chairman of the Committee. Those appointed as voting members shall include persons who are experienced in research and the delivery of services to individuals with Alzheimer's disease or a related disorder ~~victims~~ and their families. Such members shall include 3 ~~4~~

physicians licensed to practice medicine in all of its branches, ~~one representative of a postsecondary educational institution which administers or is affiliated with a medical center in the State,~~ one representative of a licensed hospital, one registered nurse with a specialty in geriatric or dementia care, one representative of a long term care facility under the Nursing Home Care Act, one representative of a long term care facility under the Assisted Living and Shared Housing Act, one representative from a supportive living facility specially serving individuals with dementia, one representative of a home care agency serving individuals with dementia, one representative of a hospice with a specialty in palliative care for dementia, one representative of an area agency on aging as defined by Section 3.07 of the Illinois Act on the Aging, one representative from a leading advocacy organization serving individuals with Alzheimer's disease, one licensed social worker, one representative of law enforcement, 2 individuals with early-stage Alzheimer's disease, 3 ~~of an organization established under the Illinois Insurance Code for the purpose of providing health insurance,~~ 5 family members or representatives of individuals with ~~victims of~~ Alzheimer's disease and related disorders, and 3 4 members of the general public. Among the physician appointments shall be persons with specialties in the fields of neurology, family medicine, psychiatry and pharmacology. Among the general public members, at least 2 appointments shall include persons 65 years of age

or older.

In addition to the 23 ~~21~~ voting members, ~~the Secretary of Human Services (or his or her designee) and one additional representative of the Department of Human Services designated by the Secretary plus~~ the Directors of the following State agencies or their designees who are qualified to represent each Department's programs and services for those with Alzheimer's disease or related disorders shall serve as nonvoting members: Department on Aging, Department of Healthcare and Family Services, Department of Public Health, Department of Human Services, and Guardianship and Advocacy Commission.

Each voting member appointed by the Director of Public Health shall serve for a term of 2 years, and until his successor is appointed and qualified. Members of the Committee shall not be compensated but shall be reimbursed for expenses actually incurred in the performance of their duties. No more than 12 ~~11~~ voting members may be of the same political party. Vacancies shall be filled in the same manner as original appointments.

The Committee shall review all State programs and services provided by State agencies that are directed toward persons with Alzheimer's disease and related dementias, and by consensus recommend changes to improve the State's response to this serious health problem. Such recommendations shall be included in the State plan described in this Act.

(Source: P.A. 95-331, eff. 8-21-07.)

(410 ILCS 405/7) (from Ch. 111 1/2, par. 6957)

Sec. 7. Regional ADA center funding. Pursuant to appropriations enacted by the General Assembly, the Department shall provide funds to hospitals affiliated with each Regional ADA Center for necessary research and for the development and maintenance of services for individuals with ~~victims of~~ Alzheimer's disease and related disorders and their families. For the fiscal year beginning July 1, 2003, and each year thereafter, the Department shall effect payments under this Section to hospitals affiliated with each Regional ADA Center through the Department of Healthcare and Family Services (formerly Illinois Department of Public Aid) under the Excellence in Alzheimer's Disease Center Treatment Act. The Department of Healthcare and Family Services shall annually report to the Advisory Committee established under this Act regarding the funding of centers under this Act. The Department shall include the annual expenditures for this purpose in the plan required by Section 5 of this Act.

(Source: P.A. 95-331, eff. 8-21-07.)