

1 AN ACT concerning public health.

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

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

6 (410 ILCS 405/2) (from Ch. 111 1/2, par. 6952)

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

1 person without Alzheimer's disease in the same age group and
2 that 71% of all Illinois nursing home residents have some
3 degree of cognitive impairment, with more than half of that
4 group having moderate to severe cognitive decline ~~finds that~~
5 ~~50% of all nursing home admissions in the State may be~~
6 ~~attributable to the Alzheimer's disease and related disorders~~
7 ~~and that these conditions are the fourth leading cause of death~~
8 ~~among the elderly.~~

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

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

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

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

22 (410 ILCS 405/3) (from Ch. 111 1/2, par. 6953)

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

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

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

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

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

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

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

26 (2) information, referral, and service coordination

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

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

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

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

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

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

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

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

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

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

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

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

16 (410 ILCS 405/4) (from Ch. 111 1/2, par. 6954)

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

1 include all of the following:

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

12 (410 ILCS 405/5) (from Ch. 111 1/2, par. 6955)

13 Sec. 5. State ADA Plan. By January 1, 2014 ~~1987~~, and every
14 3 years thereafter, the Department shall prepare a State
15 Alzheimer's Disease Assistance Plan in consultation with the
16 Advisory Committee to guide research, diagnosis, referral and
17 treatment services within each service area described by the
18 Department. To ensure meaningful input by stakeholders into the
19 plan, the Department or members of the General Assembly or
20 other interested parties may hold public hearings at locations
21 throughout the State for input by consumers and providers of
22 care. The Department or members of the General Assembly or
23 other interested parties may also utilize technological means
24 or work with advocacy organizations that have technological
25 capability, such as Webcasts or online surveys, to gather

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

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

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

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

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

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

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

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

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

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

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

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

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

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

1 of State-supported respite care to assist families;

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

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

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

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

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

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

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

15 (410 ILCS 405/6) (from Ch. 111 1/2, par. 6956)

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

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

1 or older.

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

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

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

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

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

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

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