



97TH GENERAL ASSEMBLY

State of Illinois

2011 and 2012

HB4548

Introduced 2/1/2012, by Rep. Patricia R. Bellock

SYNOPSIS AS INTRODUCED:

410 ILCS 405/2	from Ch. 111 1/2, par. 6952
410 ILCS 405/3	from Ch. 111 1/2, par. 6953
410 ILCS 405/4	from Ch. 111 1/2, par. 6954
410 ILCS 405/5	from Ch. 111 1/2, par. 6955
410 ILCS 405/6	from Ch. 111 1/2, par. 6956
410 ILCS 405/7	from Ch. 111 1/2, par. 6957

Amends the Alzheimer's Disease Assistance Act. Makes changes to the Act's policy declaration. Changes the definition of "Alzheimer's disease" and sets forth definitions for "dementia", "related disorders", and "dementia-capable State". Provides that by January 1, 2014 (instead of 1987), and every 3 years thereafter, the Department of Public Health shall prepare a State Alzheimer's Disease Assistance Plan and sets forth provisions with regard to the plan concerning public hearings, gathering feedback on recommendations, input from agencies and stakeholders, purpose and directive, and the examination of certain subject matter. Makes changes to the composition of the Alzheimer's Disease Advisory Committee. Makes other changes.

LRB097 16854 RPM 62037 b

FISCAL NOTE ACT
MAY APPLY

A BILL FOR

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 dementia affects Alzheimer's disease and related
15 disorders are devastating health conditions which destroy
16 certain vital cells of the brain and which affect an estimated
17 5,400,000 4,500,000 Americans;. This means that approximately
18 210,000 200,000 Illinois citizens have Alzheimer's disease ~~are~~
19 ~~victims~~. The General Assembly also recognizes that the
20 incidence of Alzheimer's disease is rising and expected to
21 reach 240,000 in Illinois by 2025. The General Assembly finds
22 that Medicaid costs for individuals with Alzheimer's disease
23 are 9 times higher than the costs for a person without

1 Alzheimer's disease in the same age group and that 71% of all
2 Illinois nursing home residents have some degree of cognitive
3 impairment, with more than half of that group having moderate
4 to severe cognitive decline ~~finds that 50% of all nursing home~~
5 ~~admissions in the State may be attributable to the Alzheimer's~~
6 ~~disease and related disorders and that these conditions are the~~
7 ~~fourth leading cause of death among the elderly.~~

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

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

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

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

21 (410 ILCS 405/3) (from Ch. 111 1/2, par. 6953)

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

23 (a) "Alzheimer's disease ~~and related disorders~~" or
24 "Alzheimer's" or "AD" means the most common form of dementia
25 that causes problems with memory, thinking, and behavior.

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

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

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

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

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

25 (2) information, referral, and service coordination
26 systems that provide person-centered services to people

1 with dementia and their caregivers;

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

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

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

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

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

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

1 related disorders pursuant to policies, standards, criteria
2 and procedures adopted under an affiliation agreement with a
3 Regional ADA Center under this Act.

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

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

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

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

15 (410 ILCS 405/4) (from Ch. 111 1/2, par. 6954)

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

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

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

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

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

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

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

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

1 related disorders;

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

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

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

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

24 (e) Policies, procedures, standards and criteria,
25 including medical and financial eligibility factors,
26 governing admission to and utilization of the programs,

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

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

11 (410 ILCS 405/5) (from Ch. 111 1/2, par. 6955)

12 Sec. 5. State ADA Plan. By January 1, 2014 ~~1987~~, and every
13 3 years thereafter, the Department shall prepare a State
14 Alzheimer's Disease Assistance Plan in consultation with the
15 Advisory Committee to guide research, diagnosis, referral and
16 treatment services within each service area described by the
17 Department. To ensure meaningful input by stakeholders into the
18 plan, the Department shall hold 2 public hearings at locations
19 throughout the State for input by consumers and providers of
20 care. The Department shall also utilize technological means or
21 work with advocacy organizations that have technological
22 capability, such as Webcasts or online surveys, to gather
23 feedback on recommendations from persons and families affected
24 by Alzheimer's disease and the general public. State agencies
25 with programs serving the population impacted by Alzheimer's

1 shall also present testimony at one of the State hearings to
2 specify how they are meeting the needs of people with
3 Alzheimer's. Various stakeholders, including related consumer
4 organizations or advocacy organizations as well as individuals
5 with Alzheimer's disease or a related disorder and caregivers
6 of such individuals, shall also be invited to provide public
7 comment.

8 The plan is directed to assess the current and future
9 impact of Alzheimer's disease on Illinois residents; to examine
10 the existing industries, services, and resources addressing
11 the needs of persons with Alzheimer's, their families, and
12 caregivers; and to develop a strategy to mobilize a State
13 response to this public health crisis. The plan shall include
14 an examination of the following in its assessment and
15 recommendations:

16 (1) Trends in State Alzheimer's population and needs,
17 including the changing population with dementia,
18 including, but not limited to, the use of State
19 surveillance data of persons with Alzheimer's disease for
20 purposes of having proper estimates of the number of
21 persons in the State with Alzheimer's disease.

22 (2) The current economic impact of Alzheimer's disease
23 and related disorders for the State, including the cost of
24 direct and indirect care paid by Medicaid, other
25 federal-State funded programs, the estimated direct and
26 indirect costs of family caregiving, and the cost of

1 Alzheimer's disease to businesses in Illinois.

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

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

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

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

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

17 (e) availability of and amount spent by the State
18 on home and community-based resources for persons with
19 Alzheimer's and related disorders and the availability
20 of State-supported respite care to assist families;

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

26 (g) inventory of geriatric-psychiatric units for

1 persons with behavior disorders associated with
2 Alzheimer's and related disorders;

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

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

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

20 The plan shall also indicate the number of persons served,
21 the extent of services provided, and the resources required for
22 the delivery of services through the ADA networks established
23 under this Act. Such plan shall identify and describe the
24 duties and accomplishments of each Regional ADA Center, the
25 primary Alzheimer's providers and other various providers of
26 service within the ADA network of the described service area.

1 The Department shall consult with and take into consideration
2 the plans of local and State comprehensive health planning
3 agencies recognized under the Comprehensive Health Planning
4 Act, as well as recommendations regarding Alzheimer's disease
5 and related disorders that may be included in the State Health
6 Improvement Plan.

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

8 (410 ILCS 405/6) (from Ch. 111 1/2, par. 6956)

9 Sec. 6. ADA Advisory Committee. There is created the
10 Alzheimer's Disease Advisory Committee consisting of 23 ~~21~~
11 voting members appointed by the Director of the Department, as
12 well as 5 nonvoting members as hereinafter provided in this
13 Section. The Director or his designee shall serve as one of the
14 23 ~~21~~ voting members and as the Chairman of the Committee.
15 Those appointed as voting members shall include persons who are
16 experienced in research and the delivery of services to
17 individuals with Alzheimer's disease or a related disorder
18 ~~victims~~ and their families. Such members shall include 3 ~~4~~
19 physicians licensed to practice medicine in all of its
20 branches, ~~one representative of a postsecondary educational~~
21 ~~institution which administers or is affiliated with a medical~~
22 ~~center in the State,~~ one representative of a licensed hospital,
23 one registered nurse with a specialty in geriatric or dementia
24 care, one representative of a long term care facility under the
25 Nursing Home Care Act, one representative of a long term care

1 facility under the Assisted Living and Shared Housing Act, one
2 representative from a supportive living facility specially
3 servicing individuals with dementia, one representative of a home
4 care agency servicing individuals with dementia, one
5 representative of a hospice with a specialty in palliative care
6 for dementia, one representative of an area agency on aging as
7 defined by Section 3.07 of the Illinois Act on the Aging, one
8 representative from a leading advocacy organization servicing
9 individuals with Alzheimer's disease, one licensed social
10 worker, one representative of law enforcement, 2 individuals
11 with early-stage Alzheimer's disease, 3 ~~of an organization~~
12 ~~established under the Illinois Insurance Code for the purpose~~
13 ~~of providing health insurance,~~ 5 family members or
14 representatives of individuals with ~~victims of~~ Alzheimer's
15 disease and related disorders, and 3 ~~4~~ members of the general
16 public. Among the physician appointments shall be persons with
17 specialties in the fields of neurology, family medicine,
18 psychiatry and pharmacology. Among the general public members,
19 at least 2 appointments shall include persons 65 years of age
20 or older.

21 In addition to the 23 ~~21~~ voting members, ~~the Secretary of~~
22 ~~Human Services (or his or her designee) and one additional~~
23 ~~representative of the Department of Human Services designated~~
24 ~~by the Secretary plus~~ the Directors of the following State
25 agencies or their designees who are qualified to represent each
26 Department's programs and services for those with Alzheimer's

1 disease or related disorders shall serve as nonvoting members:
2 Department on Aging, Department of Healthcare and Family
3 Services, Department of Public Health, Department of Human
4 Services, and Guardianship and Advocacy Commission.

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

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

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

20 (410 ILCS 405/7) (from Ch. 111 1/2, par. 6957)

21 Sec. 7. Regional ADA center funding. Pursuant to
22 appropriations enacted by the General Assembly, the Department
23 shall provide funds to hospitals affiliated with each Regional
24 ADA Center for necessary research and for the development and
25 maintenance of services for individuals with ~~victims of~~

1 Alzheimer's disease and related disorders and their families.
2 For the fiscal year beginning July 1, 2003, and each year
3 thereafter, the Department shall effect payments under this
4 Section to hospitals affiliated with each Regional ADA Center
5 through the Department of Healthcare and Family Services
6 (formerly Illinois Department of Public Aid) under the
7 Excellence in Alzheimer's Disease Center Treatment Act. The
8 Department of Healthcare and Family Services shall annually
9 report to the Advisory Committee established under this Act
10 regarding the funding of centers under this Act. The Department
11 shall include the annual expenditures for this purpose in the
12 plan required by Section 5 of this Act.

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