THE GENERAL ASSEMBLY OF PENNSYLVANIA

SENATE BILL No. 840 Session of 2023

INTRODUCED BY BROWN, ARGALL, HAYWOOD, LANGERHOLC, COMITTA, SCHWANK, COSTA, CAPPELLETTI, FLYNN, CULVER, BREWSTER, MILLER, MUTH, L. WILLIAMS, PENNYCUICK, COLLETT, FARRY, TARTAGLIONE, BAKER AND SANTARSIERO, JULY 11, 2023

SENATOR JUDY WARD, AGING AND YOUTH, AS AMENDED, JUNE 4, 2024

AN ACT

1 2 3	Establishing the Alzheimer's Disease and Related Disorders Division, the Alzheimer's Disease and Related Disorders Advisory Committee and the Alzheimer's Disease and Related	<
5 4 5 6 7	Disorders State Plan; and making an appropriation. ESTABLISHING THE ALZHEIMER'S, DEMENTIA AND RELATED DISORDERS OFFICE AND THE ALZHEIMER'S, DEMENTIA AND RELATED DISORDERS ADVISORY COMMITTEE.	<
8	The General Assembly of the Commonwealth of Pennsylvania	
9	hereby enacts as follows:	
10	Section 1. Short title.	
11	This act shall be known and may be cited as the Alzheimer's	
12	Disease, DEMENTIA and Related Disorders Public Health	<
13	Infrastructure Act.	
14	Section 2. Definitions.	
15	The following words and phrases when used in this act shall	
16	have the meanings given to them in this section unless the	
17	context clearly indicates otherwise:	
18	"Advisory committee." The Alzheimer's Disease , DEMENTIA and	<
19	Related Disorders Advisory Committee established under section	

1 4.

2 "Alzheimer's disease, DEMENTIA and related disorders." An <---3 irreversible and progressive neurological disorder diagnosed by a physician that has all of the following characteristics: 4 5 The disorder causes cognitive decline and memory (1)6 impairment, behavioral and psychiatric problems and loss of 7 the ability to care for oneself. 8 (2) The disorder is severe enough to interfere with work 9 or social activities and requires continuous care or 10 supervision. "Annual survey." The Centers for Disease Control and 11 <---Prevention Behavioral Risk Factor Surveillance System annual 12 13 survey. 14 "Department." The Department of Health AGING of the <---15 Commonwealth. 16 "Director." An individual appointed by the secretary to oversee operations and responsibilities of the division OFFICE. 17 <---18 "Division." The Alzheimer's Disease and Related Disorders <---19 Division established under section 3. 20 "OFFICE." THE ALZHEIMER'S, DEMENTIA AND RELATED DISORDERS <---21 OFFICE ESTABLISHED UNDER SECTION 3. 22 "Secretary." The Secretary of Health AGING of the <---23 Commonwealth. 24 "State Plan." The PENNSYLVANIA STATE PLAN FOR Alzheimer's <---25 Disease, DEMENTIA and Related Disorders State Plan established <---26 under section 5 PURSUANT TO EXECUTIVE ORDER 2013-01 OR A <---SUCCESSOR STATE PLAN ESTABLISHED PURSUANT TO A DEPARTMENTAL 27 POLICY OR REGULATION. 28 29 Section 3. Alzheimer's Disease, DEMENTIA and Related Disorders <--30 Division OFFICE. <---

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(a) Establishment.--The Alzheimer's Disease, DEMENTIA and <--
 Related Disorders Division OFFICE is established within the <--
 department.

4 (b) Director.--The position of director is established as a
5 full-time position to oversee operations of the division. The
6 director shall be responsible for the following: OFFICE.
7 (C) DUTIES.--THE OFFICE SHALL HAVE THE FOLLOWING POWERS AND

8 RESPONSIBILITIES:

9 (1) Oversight of activities associated with and relevant 10 to the successful implementation of the State Plan.

11 (2) Providing strategic direction and support to the 12 advisory committee, such as leading the required updates to 13 the State Plan.

14 (3) Establishing and maintaining relationships with
15 other State COMMONWEALTH agencies and organizations within <--
16 this Commonwealth to foster public-private collaboration in
17 order to meet the needs of the affected population and
18 prevent duplication of services.

19 (4) Evaluating existing Alzheimer's and dementia, <--
 20 DEMENTIA AND RELATED DISORDERS programs and services.

(5) Identifying service gaps within the Commonwealth.
(6) Increasing awareness of and facilitating access to
quality, coordinated care for individuals with dementia
ALZHEIMER'S, DEMENTIA AND RELATED DISORDERS.

(7) Utilizing dementia related ALZHEIMER'S, DEMENTIA AND <--
 RELATED DISORDERS data to coordinate AND COLLABORATE with the <--
 department OTHER COMMONWEALTH AGENCIES to improve public <--
 health outcomes.

29 (8) Identifying and managing grants to assist in the
 30 funding of the division, State Plan implementation and other

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1 programs and services to assist this Commonwealth in becoming

2 dementia-capable.

3 (9) With the advice and consent of the advisory
4 committee, compiling and submitting to the members under
5 section 4(b)(5), an annual report outlining key division
6 deliverables, such as population data and statistics updates,
7 funding through grant applications and State Plan

8 implementation status.

9 (8) NO LESS THAN EVERY FIVE YEARS, AND IN CONSULTATION <---10 WITH THE ADVISORY COMMITTEE, CONDUCT A REVIEW OF THE EXISTING 11 STATE PLAN TO EVALUATE CHANGES IN TRENDS, SCIENTIFIC AND 12 RESEARCH ADVANCEMENTS, GAPS IN SERVICES AND OTHER EMERGING 13 ISSUES IMPACTING THIS POPULATION AND TO DETERMINE IF 14 AMENDMENTS ARE NECESSARY.

15 (9) IN CONSULTATION WITH THE ADVISORY COMMITTEE, APPROVE16 AND IMPLEMENT AMENDMENTS TO THE STATE PLAN.

17 (10) IDENTIFYING AND MANAGING GRANTS TO ASSIST IN THE
18 FUNDING OF THE OFFICE, STATE PLAN IMPLEMENTATION AND OTHER
19 PROGRAMS AND SERVICES TO ASSIST THIS COMMONWEALTH IN BECOMING
20 DEMENTIA-CAPABLE.

(11) IN CONSULTATION WITH THE ADVISORY COMMITTEE,
COMPILE AN ANNUAL REPORT, WHICH SHALL BE MADE AVAILABLE ON
THE DEPARTMENT'S PUBLICLY ACCESSIBLE INTERNET WEBSITE,
OUTLINING KEY OFFICE DELIVERABLES, SUCH AS POPULATION DATA
AND STATISTICS UPDATES, FUNDING THROUGH GRANT APPLICATIONS
AND STATE PLAN IMPLEMENTATION STATUS.

Section 4. Alzheimer's Disease, DEMENTIA and Related Disorders <--
 Advisory Committee.

29 (a) Establishment.--The Alzheimer's Disease, DEMENTIA and <--
 30 Related Disorders Advisory Committee is established in the

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1 department.

2	(b)	MembershipThe	advisory	committee	shall	consist	of	the	
3	followin	ng members:							

4	(1) The secretary.	<
5	(2) The Secretary of Aging.	
6	(3) The Secretary of Human Services.	
7	(4) The Secretary of Labor and Industry.	
8	(5) The chair and minority chair of the Aging and Youth-	
9	Committee of the Senate, the chair and minority chair of the-	
10	Aging and Older Adult Services Committee of the House of	
11	Representatives, the chair and minority chair of the Health	
12	and Human Services Committee of the Senate and the chair and	
13	minority chair of the Health Committee of the House of	
14	Representatives.	
15	(6) An individual living with Alzheimer's disease and an	-
16	individual living with another type of dementia.	
17	(7) An unpaid caregiver of an individual with	
18	Alzheimer's disease or a related disorder.	
19	(8) An individual representing a Statewide association	
20	dedicated to Alzheimer's care, support and research.	
21	(9) A physician who has experience diagnosing and	
22	treating Alzheimer's disease and related disorders.	
23	(10) An individual representing the Pennsylvania Society	_
24	for Post-Acute and Long-Term Care Medicine.	
25	(11) A psychologist who specializes in dementia care.	
26	(12) An individual representing hospitals and health	
27	systems.	
28	(13) An individual representing community health	
29	centers.	
30	(14) An individual who conducts research regarding	
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1	Alzheimer's disease and related disorders.
2	(15) An individual representing Pennsylvania's Medicaid
3	Managed Care Organizations.
4	(16) An individual specializing in population health
5	management.
6	(17) Two individuals representing community based
7	organizations that have demonstrated experience and expertise
8	in addressing the employment, training or education needs of
9	the health care and direct care workforce providing
10	professional care for individuals living with dementia.
11	(18) An individual from a nongovernmental Statewide
12	organization that advocates for seniors.
13	(19) Five individuals representing the long term care
14	continuum, including one representative from each of the-
15	following:
16	(i) Nonprofit skilled nursing facilities.
17	(ii) For-profit skilled nursing facilities.
18	(iii) Assisted living residences or personal care
19	homes.
20	(iv) Home care organizations or hospices.
21	(v) Older adult daily living centers.
22	(20) A representative of the local area agencies on
23	aging.
24	(21) A representative from the Pennsylvania Long-Term-
25	Care Ombudsman Program.
26	(1) THE SECRETARY OR A DESIGNEE. <
27	(2) THE SECRETARY OF HEALTH OR A DESIGNEE.
28	(3) THE SECRETARY OF HUMAN SERVICES OR A DESIGNEE.
29	(4) THE SECRETARY OF LABOR AND INDUSTRY OR A DESIGNEE.
30	(5) THE CHAIR AND MINORITY CHAIR OF THE AGING AND YOUTH

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COMMITTEE OF THE SENATE OR DESIGNEES AND THE CHAIR AND
 MINORITY CHAIR OF THE AGING AND OLDER ADULT SERVICES
 COMMITTEE OF THE HOUSE OF REPRESENTATIVES OR DESIGNEES.

4

(6) A MEMBER FROM THE PENNSYLVANIA COUNCIL ON AGING.

5 (7) BUREAU DIRECTOR REPRESENTING THE PHARMACEUTICAL
6 ASSISTANCE CONTRACT FOR THE ELDERLY PROGRAM.

7 (8) AN INDIVIDUAL LIVING WITH ALZHEIMER'S, DEMENTIA OR A
8 RELATED DISORDER OR A DESIGNEE.

9 (9) A FAMILY MEMBER OF OR A CAREGIVER FOR A PERSON
10 LIVING WITH ALZHEIMER'S, DEMENTIA OR A RELATED DISORDER.

(10) AN ATTORNEY WITH AT LEAST FIVE YEARS' EXPERIENCE IN
 PROVIDING LEGAL REPRESENTATION TO OLDER ADULTS WITH COGNITIVE
 DISEASES AND RELATED DISORDERS.

14 (11) THREE INDIVIDUALS FROM NON-GOVERNMENTAL STATEWIDE
 15 ORGANIZATIONS THAT ADVOCATE FOR OLDER ADULTS.

16 (12) A PHYSICIAN WITH AT LEAST FIVE YEARS' EXPERIENCE IN
17 DIAGNOSING AND TREATING ALZHEIMER'S, DEMENTIA AND RELATED
18 DISORDERS.

19 (13) TWO INDIVIDUALS WHO CONDUCT RESEARCH REGARDING
20 ALZHEIMER'S, DEMENTIA AND RELATED DISORDERS.

21 (14) AN INDIVIDUAL REPRESENTING THE LOCAL AREA AGENCIES22 ON AGING.

23 (15) AN INDIVIDUAL REPRESENTING THE COMMONWEALTH'S24 HOSPITALS AND HEALTH SYSTEMS.

(16) AN INDIVIDUAL REPRESENTING THE FACILITIES IN THECOMMONWEALTH THAT PROVIDE LONG-TERM CARE TO INDIVIDUALS.

27 (17) AN INDIVIDUAL REPRESENTING THE COMMONWEALTH'S28 COMMUNITY HEALTH CENTERS IN RURAL AND URBAN COMMUNITIES.

29 (18) AN INDIVIDUAL REPRESENTING OLDER ADULT DAY LIVING30 CENTERS.

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1 (19) AN INDIVIDUAL REPRESENTING THE LIFE PROVIDERS.

2 (20) AN INDIVIDUAL REPRESENTING A FEDERALLY QUALIFIED3 HEALTH CENTER.

4 (21) AN INDIVIDUAL REPRESENTING THE PENNSYLVANIA SOCIETY
5 FOR POST-ACUTE AND LONG-TERM CARE MEDICINE.

6 (22) AN INDIVIDUAL REPRESENTING A STATEWIDE ASSOCIATION
7 DEDICATED TO ALZHEIMER'S CARE, SUPPORT AND RESEARCH.

8 (C) Appointments.--Except for members under subsection (b) <---9 (5) (B) (1), (2), (3), (4) AND (5), members of the advisory <---10 committee shall be appointed by the Governor to four-year staggered terms. The MEMBERS OF THE GOVERNOR'S CABINET AND 11 <---12 sitting members of the Senate and the House of Representatives 13 shall be appointed to a term corresponding to their THE MEMBER'S <--14 term of office.

15 (d) Chair.—The Governor shall appoint a chair from among <--16 the members of the advisory committee to serve a term of four 17 years.

18 (e) Powers and duties. The advisory committee shall meet on 19 a quarterly basis at minimum and shall have the following powers-20 and duties:

21 (1) To assess the current and future impact of

22 Alzheimer's disease and related disorders on residents of

23 this Commonwealth.

24 (2) To examine the existing industries, services and
 25 resources addressing the needs of persons with Alzheimer's
 26 disease and related disorders, their families and caregivers.
 27 (3) To develop strategies to mobilize a Statewide

28 response to the public health crisis created by Alzheimer's

- 29 disease and related disorders.
- 30 (4) To develop the State Plan and advise the department

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1	on necessary updates and implementation of the State Plan.
2	Section 5. Alzheimer's Disease and Related Disorders State
3	Plan.
4	(a) Establishment. The advisory committee shall develop a
5	State Plan that outlines a strategy to mobilize the
6	Commonwealth's response to Alzheimer's disease and related
7	disorders and make policy recommendations to make this
8	Commonwealth a more dementia capable State. In developing the
9	State Plan, the advisory committee shall examine the following:
10	(1) Trends in the Commonwealth's Alzheimer's disease and
11	related disorders populations and service needs, such as:
12	(i) The Commonwealth's role in providing or
13	facilitating long-term care, family caregiver support and
14	assistance to individuals with early-stage or early-onset-
15	Alzheimer's disease and related disorders.
16	(ii) The Commonwealth's policies regarding-
17	individuals with Alzheimer's disease and related
18	disorders.
19	(iii) The fiscal impact of Alzheimer's disease and
20	related disorders on publicly funded health care
21	programs.
22	(iv) The establishment of a surveillance system to
23	better determine the number of individuals diagnosed with
24	Alzheimer's disease and related disorders and to monitor-
25	changes to the number of individuals diagnosed with
26	Alzheimer's disease and related disorders.
27	(2) Existing resources, services and capacity relating
28	to the diagnosis and care of individuals living with
29	Alzheimer's disease and related disorders, such as:
30	(i) Type, cost and availability of Alzheimer's

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1	disease and related disorders care services.
2	(ii) The availability of health care workers who can-
3	serve individuals with dementia, such as neurologists,
4	geriatricians and direct care workers.
5	(iii) Dementia specific training requirements for
6	public and private employees who interact with
7	individuals living with Alzheimer's and related
8	disorders, such as long term care workers, case managers,
9	adult protective services, law enforcement and first-
10	responders.
11	(iv) Home-based and community-based services, such-
12	as respite care for individuals diagnosed with
13	Alzheimer's disease and other disorders and their-
14	families.
15	(v) Quality care measures for home based and
16	community based services and residential care facilities.
17	(vi) State-supported Alzheimer's and related-
18	disorders research conducted at universities located in
19	this Commonwealth.
20	(3) Policies and strategies that address:
21	(i) Increasing public awareness of Alzheimer's-
22	disease and related disorders.
23	(ii) Educating health care providers to increase
24	early detection and diagnosis of Alzheimer's disease and
25	related disorders.
26	(iii) Improving the health care received by
27	individuals diagnosed with Alzheimer's disease and
28	related disorders.
29	(iv) Evaluating the capacity of the health care
30	system in meeting the growing number and needs of

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1	individuals with Alzheimer's disease and related
2	disorders.
3	(v) Increasing the number of health care
4	professionals available to treat the growing member of
5	individuals with Alzheimer's disease and related-
6	disorders.
7	(vi) Improving services provided in the home and
8	community to delay and decrease the need for
9	institutionalized care for individuals with Alzheimer's
10	disease and related disorders.
11	(vii) Improving long-term care, such as assisted-
12	living, for individuals with Alzheimer's disease and
13	related disorders.
14	(viii) Assisting unpaid Alzheimer's disease and
15	related disorders caregivers.
16	(ix) Increasing and improving research on
17	Alzheimer's disease and related disorders.
18	(x) Promoting activities to maintain and improve
19	brain health.
20	(xi) Improving the collection of data and
21	information related to Alzheimer's disease and related
22	disorders and their public health burdens.
23	(xii) Improving public safety for and addressing the
24	safety related needs of individuals with Alzheimer's
25	disease and related disorders.
26	(xiii) Addressing legal protections for and legal
27	issues faced by individuals with Alzheimer's disease and
28	related disorders.
29	(xiv) Improving the ways in which the Commonwealth
30	evaluates and adopts policies to assist individuals

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1 diagnosed with Alzheimer's disease and related disorders

2 and their families.

3 (b) Update. The State Plan shall be updated every five

4 years to capture changes in trends, scientific and research

5 advancements, gaps in services and other emerging issues

6 impacting the Alzheimer's disease and related disorders

7 population.

8 Section 6. Data collection.

9 The department shall include the Caregiver Module and

10 Cognitive Decline Module in the annual survey on a rotating

11 annual basis to collect prevalence data, track trends over time-

12 and analyze data to direct public health programs and resources.

13 Section 7. Appropriation.

14 The amount of \$750,000 is appropriated annually to the

15 department for implementation and maintenance of this act.

16 (D) TERM.--MEMBERS SHALL BE ELIGIBLE FOR REAPPOINTMENT BUT <--
17 SHALL SERVE NO MORE THAN TWO CONSECUTIVE FULL TERMS. MEMBERS
18 SHALL SERVE UNTIL A SUCCESSOR IS APPOINTED AND QUALIFIED,
19 PROVIDED THE SUCCESSOR REPRESENTS THE INTERESTS OF THE
20 MEMBERSHIP CLASS FOR WHICH THE MEMBER WAS APPOINTED.

(E) VACANCIES.--ANY VACANCY OF THE ADVISORY COMMITTEE SHALL
BE FILLED BY THE ORIGINAL APPOINTING AUTHORITY. AN INDIVIDUAL
APPOINTED TO FILL A VACANCY SHALL SERVE THE BALANCE OF THE
PREVIOUS MEMBER'S TERM.

25 (F) REMOVAL.--MEMBERS MAY BE REMOVED FROM THE COMMITTEE FOR 26 THE FOLLOWING REASONS:

(1) A MEMBER WHO FAILS TO ATTEND THREE CONSECUTIVE
MEETINGS SHALL FORFEIT THE MEMBER'S SEAT UNLESS THE
CHAIRPERSON, UPON WRITTEN REQUEST FROM THE MEMBER, FINDS THAT
THE MEMBER SHOULD BE EXCUSED FROM A MEETING.

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1 (2) A MEMBER SHALL FORFEIT THE MEMBER'S SEAT IF THE 2 MEMBER NO LONGER REPRESENTS THE INTERESTS OF THE MEMBERSHIP 3 CLASS FOR WHICH THE MEMBER WAS APPOINTED. A MEMBER MEETING 4 THE THRESHOLD UNDER THIS PARAGRAPH SHALL NO LONGER BE 5 EMPLOYED OR ASSOCIATED WITH THE INTERESTS OF THE RESPECTIVE 6 QUALIFICATIONS FOR WHICH THE MEMBER WAS APPOINTED.

7 (G) EXPENSES.--MEMBERS MAY NOT RECEIVE COMPENSATION OR
8 REMUNERATION FOR SERVICE AS ADVISORY COMMITTEE MEMBERS.
9 NONGOVERNMENTAL ADVISORY COMMITTEE MEMBERS SHALL BE ENTITLED TO
10 REIMBURSEMENT FOR TRAVEL AND RELATED ACTUAL EXPENSES ACCRUED IN
11 THE PERFORMANCE OF THE DUTIES AS MEMBERS, IN ACCORDANCE WITH
12 COMMONWEALTH TRAVEL POLICY.

(H) DESIGNEE.--GOVERNMENTAL MEMBERS AND THE MEMBER WHO IS
LIVING WITH ALZHEIMER'S, DEMENTIA OR RELATED DISORDER MAY
APPOINT A DESIGNEE TO ATTEND AND VOTE AT MEETINGS OF THE
ADVISORY COMMITTEE. EACH MEMBER WHO APPOINTS A DESIGNEE SHALL DO
SO BY SENDING A LETTER TO THE CHAIRPERSON STATING THE NAME OF
THE DESIGNEE.

(I) CHAIR.--THE CHAIR OF THE ADVISORY COMMITTEE SHALL BE THE
 SECRETARY OR A DESIGNEE.

(J) VICE CHAIR.--THE VICE CHAIR OF THE COMMITTEE SHALL BETHE SECRETARY OF HEALTH OR A DESIGNEE.

23 SECTION 5. POWERS AND DUTIES OF THE ADVISORY COMMITTEE.

(A) COMMITTEE.--THE ADVISORY COMMITTEE SHALL MEET ON A
QUARTERLY BASIS AT MINIMUM AND SHALL HAVE THE FOLLOWING POWERS
AND DUTIES:

(1) ASSESS THE CURRENT AND FUTURE IMPACT OF ALZHEIMER'S,
 DEMENTIA AND RELATED DISORDERS ON RESIDENTS OF THIS
 COMMONWEALTH.

30 (2) EXAMINE THE EXISTING INDUSTRIES, SERVICES AND 20230SB0840PN1676 - 13 - RESOURCES ADDRESSING THE NEEDS OF PERSONS WITH ALZHEIMER'S,
 DEMENTIA AND RELATED DISORDERS, THEIR FAMILIES AND
 CAREGIVERS.

4 (3) DEVELOP STRATEGIES TO MOBILIZE A STATEWIDE RESPONSE
5 TO ALZHEIMER'S, DEMENTIA AND RELATED DISORDERS.

6 (4) ADVISE THE DEPARTMENT ON NECESSARY UPDATES AND
7 IMPLEMENTATION OF THE STATE PLAN.

8 (5) CONSULT WITH VARIOUS COMMONWEALTH AGENCIES AND TO 9 MAKE RECOMMENDATIONS ON REGULATIONS, LICENSURE, FINANCING OR 10 ANY OTHER RESPONSIBILITIES OF THOSE COMMONWEALTH AGENCIES 11 RELATING TO ALZHEIMER'S, DEMENTIA AND RELATED DISORDERS.

12 (6) PERFORM OTHER DUTIES AS THE GOVERNOR MAY ASSIGN13 RELATING TO ALZHEIMER'S, DEMENTIA AND RELATED DISORDERS.

14 (7) DEVELOP AND ADOPT RULES FOR CONDUCTING ADVISORY
15 COMMITTEE MEETINGS, INCLUDING, BUT NOT LIMITED TO, THE
16 PROCEDURE FOR FORMALLY ADOPTING THE APPROVAL OF COMMITTEE
17 REPORTS BEFORE RELEASE TO THE PUBLIC.

(B) SCOPE.--ALL POWERS AND DUTIES ENUMERATED IN THIS SECTION
SHALL BE PERFORMED IN A MANNER THAT ADDRESSES ALL AREAS OF
ALZHEIMER'S, DEMENTIA AND RELATED DISORDERS.

21 Section 8 6. Effective date.

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22 This act shall take effect in 180 days.

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