THE GENERAL ASSEMBLY OF PENNSYLVANIA

SENATE BILL

No. 840

Session of 2023

INTRODUCED BY BROWN, ARGALL, HAYWOOD, LANGERHOLC, COMITTA, SCHWANK, COSTA, CAPPELLETTI, FLYNN, CULVER AND BREWSTER, JULY 11, 2023

REFERRED TO AGING AND YOUTH, JULY 11, 2023

AN ACT

- 1 Establishing the Alzheimer's Disease and Related Disorders
- Division, the Alzheimer's Disease and Related Disorders
- 3 Advisory Committee and the Alzheimer's Disease and Related
- Disorders State Plan; and making an appropriation.
- 5 The General Assembly of the Commonwealth of Pennsylvania
- 6 hereby enacts as follows:
- 7 Section 1. Short title.
- 8 This act shall be known and may be cited as the Alzheimer's
- 9 Disease and Related Disorders Public Health Infrastructure Act.
- 10 Section 2. Definitions.
- 11 The following words and phrases when used in this act shall
- 12 have the meanings given to them in this section unless the
- 13 context clearly indicates otherwise:
- 14 "Advisory committee." The Alzheimer's Disease and Related
- 15 Disorders Advisory Committee established under section 4.
- 16 "Alzheimer's disease and related disorders." An irreversible
- 17 and progressive neurological disorder diagnosed by a physician
- 18 that has all of the following characteristics:

- 1 (1) The disorder causes cognitive decline and memory
- 2 impairment, behavioral and psychiatric problems and loss of
- 3 the ability to care for oneself.
- 4 (2) The disorder is severe enough to interfere with work
- 5 or social activities and requires continuous care or
- 6 supervision.
- 7 "Annual survey." The Centers for Disease Control and
- 8 Prevention Behavioral Risk Factor Surveillance System annual
- 9 survey.
- 10 "Department." The Department of Health of the Commonwealth.
- "Director." An individual appointed by the secretary to
- 12 oversee operations and responsibilities of the division.
- 13 "Division." The Alzheimer's Disease and Related Disorders
- 14 Division established under section 3.
- "Secretary." The Secretary of Health of the Commonwealth.
- "State Plan." The Alzheimer's Disease and Related Disorders
- 17 State Plan established under section 5.
- 18 Section 3. Alzheimer's Disease and Related Disorders Division.
- 19 (a) Establishment. -- The Alzheimer's Disease and Related
- 20 Disorders Division is established within the department.
- 21 (b) Director. -- The position of director is established as a
- 22 full-time position to oversee operations of the division. The
- 23 director shall be responsible for the following:
- 24 (1) Oversight of activities associated with and relevant
- 25 to the successful implementation of the State Plan.
- 26 (2) Providing strategic direction and support to the
- 27 advisory committee, such as leading the required updates to
- the State Plan.
- 29 (3) Establishing and maintaining relationships with
- 30 other State agencies and organizations within this

- 1 Commonwealth to foster public-private collaboration in order
- 2 to meet the needs of the affected population and prevent
- 3 duplication of services.
- 4 (4) Evaluating existing Alzheimer's and dementia 5 programs and services.
- 6 (5) Identifying service gaps within the Commonwealth.
- 7 (6) Increasing awareness of and facilitating access to quality, coordinated care for individuals with dementia.
- 9 (7) Utilizing dementia-related data to coordinate with 10 the department to improve public health outcomes.
- 11 (8) Identifying and managing grants to assist in the 12 funding of the division, State Plan implementation and other 13 programs and services to assist this Commonwealth in becoming 14 dementia-capable.
- (9) With the advice and consent of the advisory

 committee, compiling and submitting to the members under

 section 4(b)(5), an annual report outlining key division

 deliverables, such as population data and statistics updates,

 funding through grant applications and State Plan

 implementation status.
- 21 Section 4. Alzheimer's Disease and Related Disorders Advisory
 22 Committee.
- 23 (a) Establishment.--The Alzheimer's Disease and Related
 24 Disorders Advisory Committee is established in the department.
- 25 (b) Membership.--The advisory committee shall consist of the 26 following members:
- 27 (1) The secretary.
- 28 (2) The Secretary of Aging.
- 29 (3) The Secretary of Human Services.
- 30 (4) The Secretary of Labor and Industry.

- 1 (5) The chair and minority chair of the Aging and Youth
- 2 Committee of the Senate, the chair and minority chair of the
- 3 Aging and Older Adult Services Committee of the House of
- 4 Representatives, the chair and minority chair of the Health
- 5 and Human Services Committee of the Senate and the chair and
- 6 minority chair of the Health Committee of the House of
- 7 Representatives.
- 8 (6) An individual living with Alzheimer's disease and an
- 9 individual living with another type of dementia.
- 10 (7) An unpaid caregiver of an individual with
- 11 Alzheimer's disease or a related disorder.
- 12 (8) An individual representing a Statewide association
- dedicated to Alzheimer's care, support and research.
- 14 (9) A physician who has experience diagnosing and
- treating Alzheimer's disease and related disorders.
- 16 (10) An individual representing the Pennsylvania Society
- for Post-Acute and Long-Term Care Medicine.
- 18 (11) A psychologist who specializes in dementia care.
- 19 (12) An individual representing hospitals and health
- 20 systems.
- 21 (13) An individual representing community health
- centers.
- 23 (14) An individual who conducts research regarding
- 24 Alzheimer's disease and related disorders.
- 25 (15) An individual representing Pennsylvania's Medicaid
- 26 Managed Care Organizations.
- 27 (16) An individual specializing in population health
- 28 management.
- 29 (17) Two individuals representing community-based
- 30 organizations that have demonstrated experience and expertise

- in addressing the employment, training or education needs of
- 2 the health care and direct care workforce providing
- 3 professional care for individuals living with dementia.
- 4 (18) An individual from a nongovernmental Statewide organization that advocates for seniors.
- 6 (19) Five individuals representing the long-term care 7 continuum, including one representative from each of the 8 following:
- 9 (i) Nonprofit skilled nursing facilities.
- 10 (ii) For-profit skilled nursing facilities.
- 11 (iii) Assisted living residences or personal care
- homes.
- 13 (iv) Home care organizations or hospices.
- 14 (v) Older adult daily living centers.
- 15 (20) A representative of the local area agencies on
- 16 aging.
- 17 (21) A representative from the Pennsylvania Long-Term
- 18 Care Ombudsman Program.
- 19 (c) Appointments.--Except for members under subsection (b)
- 20 (5), members of the advisory committee shall be appointed by the
- 21 Governor to four-year staggered terms. The sitting members of
- 22 the Senate and the House of Representatives shall be appointed
- 23 to a term corresponding to their term of office.
- 24 (d) Chair. -- The Governor shall appoint a chair from among
- 25 the members of the advisory committee to serve a term of four
- 26 years.
- 27 (e) Powers and duties. -- The advisory committee shall meet on
- 28 a quarterly basis at minimum and shall have the following powers
- 29 and duties:
- 30 (1) To assess the current and future impact of

- Alzheimer's disease and related disorders on residents of this Commonwealth.
 - (2) To examine the existing industries, services and resources addressing the needs of persons with Alzheimer's disease and related disorders, their families and caregivers.
 - (3) To develop strategies to mobilize a Statewide response to the public health crisis created by Alzheimer's disease and related disorders.
- 9 (4) To develop the State Plan and advise the department 10 on necessary updates and implementation of the State Plan.
- 11 Section 5. Alzheimer's Disease and Related Disorders State
- 12 Plan.

3

4

5

6

7

8

- 13 (a) Establishment.--The advisory committee shall develop a
- 14 State Plan that outlines a strategy to mobilize the
- 15 Commonwealth's response to Alzheimer's disease and related
- 16 disorders and make policy recommendations to make this
- 17 Commonwealth a more dementia-capable State. In developing the
- 18 State Plan, the advisory committee shall examine the following:
- 19 (1) Trends in the Commonwealth's Alzheimer's disease and 20 related disorders populations and service needs, such as:
- 21 (i) The Commonwealth's role in providing or
- facilitating long-term care, family caregiver support and
- assistance to individuals with early-stage or early-onset
- 24 Alzheimer's disease and related disorders.
- 25 (ii) The Commonwealth's policies regarding
- 26 individuals with Alzheimer's disease and related
- disorders.
- 28 (iii) The fiscal impact of Alzheimer's disease and
- 29 related disorders on publicly funded health care
- 30 programs.

1 (iv) The establishment of a surveillance system to better determine the number of individuals diagnosed with 2 Alzheimer's disease and related disorders and to monitor 3 changes to the number of individuals diagnosed with 4 5 Alzheimer's disease and related disorders. Existing resources, services and capacity relating 6 7 to the diagnosis and care of individuals living with 8 Alzheimer's disease and related disorders, such as: 9 Type, cost and availability of Alzheimer's 10 disease and related disorders care services. 11 The availability of health care workers who can 12 serve individuals with dementia, such as neurologists, 13 geriatricians and direct care workers. 14 Dementia-specific training requirements for 15 public and private employees who interact with individuals living with Alzheimer's and related 16 17 disorders, such as long-term care workers, case managers, adult protective services, law enforcement and first 18 19 responders. 20 (iv) Home-based and community-based services, such 21 as respite care for individuals diagnosed with 22 Alzheimer's disease and other disorders and their families. 23 24 Quality care measures for home-based and 25 community-based services and residential care facilities. 26 (vi) State-supported Alzheimer's and related 27 disorders research conducted at universities located in 28 this Commonwealth. 29 Policies and strategies that address:

(i)

30

Increasing public awareness of Alzheimer's

disease and related disorders.

5

6

7

8

9

10

11

12

13

14

15

16

17

18

19

20

21

22

- 2 (ii) Educating health care providers to increase
 3 early detection and diagnosis of Alzheimer's disease and
 4 related disorders.
 - (iii) Improving the health care received by individuals diagnosed with Alzheimer's disease and related disorders.
 - (iv) Evaluating the capacity of the health care system in meeting the growing number and needs of individuals with Alzheimer's disease and related disorders.
 - (v) Increasing the number of health care professionals available to treat the growing member of individuals with Alzheimer's disease and related disorders.
 - (vi) Improving services provided in the home and community to delay and decrease the need for institutionalized care for individuals with Alzheimer's disease and related disorders.
 - (vii) Improving long-term care, such as assisted living, for individuals with Alzheimer's disease and related disorders.
- 23 (viii) Assisting unpaid Alzheimer's disease and 24 related disorders caregivers.
- 25 (ix) Increasing and improving research on 26 Alzheimer's disease and related disorders.
- 27 (x) Promoting activities to maintain and improve brain health.
- 29 (xi) Improving the collection of data and
 30 information related to Alzheimer's disease and related

- disorders and their public health burdens.
- 2 (xii) Improving public safety for and addressing the
- 3 safety-related needs of individuals with Alzheimer's
- 4 disease and related disorders.
- 5 (xiii) Addressing legal protections for and legal
- issues faced by individuals with Alzheimer's disease and
- 7 related disorders.
- 8 (xiv) Improving the ways in which the Commonwealth
- 9 evaluates and adopts policies to assist individuals
- 10 diagnosed with Alzheimer's disease and related disorders
- 11 and their families.
- 12 (b) Update. -- The State Plan shall be updated every five
- 13 years to capture changes in trends, scientific and research
- 14 advancements, gaps in services and other emerging issues
- 15 impacting the Alzheimer's disease and related disorders
- 16 population.
- 17 Section 6. Data collection.
- 18 The department shall include the Caregiver Module and
- 19 Cognitive Decline Module in the annual survey on a rotating
- 20 annual basis to collect prevalence data, track trends over time
- 21 and analyze data to direct public health programs and resources.
- 22 Section 7. Appropriation.
- The amount of \$750,000 is appropriated annually to the
- 24 department for implementation and maintenance of this act.
- 25 Section 8. Effective date.
- This act shall take effect in 180 days.