## THE GENERAL ASSEMBLY OF PENNSYLVANIA

## **HOUSE BILL**

No. 2400 Session of 2024

INTRODUCED BY MADDEN, KIM, SAMUELSON, KHAN, BRENNAN, M. BROWN, CEPEDA-FREYTIZ, T. DAVIS, FREEMAN, GALLAGHER, GIRAL, HARKINS, HILL-EVANS, KINSEY, MAYES, McNEILL, PROBST, PROKOPIAK, ROZZI, SANCHEZ, SCHLOSSBERG, VENKAT AND D. WILLIAMS, JUNE 5, 2024

REFERRED TO COMMITTEE ON AGING AND OLDER ADULT SERVICES, JUNE 5, 2024

## AN ACT

- 1 Establishing the Alzheimer's, Dementia and Related Disorders
- Office and the Alzheimer's, Dementia and Related Disorders
- 3 Advisory Committee.
- 4 The General Assembly of the Commonwealth of Pennsylvania
- 5 hereby enacts as follows:
- 6 Section 1. Short title.
- 7 This act shall be known and may be cited as the Alzheimer's,
- 8 Dementia and Related Disorders Act.
- 9 Section 2. Definitions.
- 10 The following words and phrases when used in this act shall
- 11 have the meanings given to them in this section unless the
- 12 context clearly indicates otherwise:
- 13 "Advisory committee." The Alzheimer's, Dementia and Related
- 14 Disorders Advisory Committee established under section 4.
- 15 "Alzheimer's, dementia and related disorders." An
- 16 irreversible and progressive neurological disorder diagnosed by
- 17 a physician 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 "Department." The Department of Aging of the Commonwealth.
- 8 "Director." An individual appointed by the secretary to
- 9 oversee operations and responsibilities of the office.
- 10 "Office." The Alzheimer's, Dementia and Related Disorders
- 11 Office established under section 3.
- "Secretary." The Secretary of Aging of the Commonwealth.
- "State Plan." The Pennsylvania State Plan for Alzheimer's,
- 14 Dementia and Related Disorders established pursuant to Executive
- 15 Order 2013-01 or a successor State Plan established pursuant to
- 16 a departmental policy or regulation.
- 17 Section 3. Alzheimer's, Dementia and Related Disorders Office.
- 18 (a) Establishment.--The Alzheimer's, Dementia and Related
- 19 Disorders Office is established within the department.
- 20 (b) Director. -- The position of director is established as a
- 21 full-time position to oversee operations of the office.
- 22 (c) Duties. -- The office shall have the following powers and
- 23 responsibilities:
- 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 Commonwealth agencies and organizations within this

- Commonwealth to foster public-private collaboration in order to meet the needs of the affected population and prevent
- 3 duplication of services.

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- 4 (4) Evaluating existing Alzheimer's, 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 Alzheimer's, dementia and related disorders.
    - (7) Utilizing Alzheimer's, dementia and related disorders data to coordinate and collaborate with other Commonwealth agencies to improve health outcomes.
    - (8) No less than every five years, and in consultation with the advisory committee, conducting a review of the existing State Plan to evaluate changes in trends, scientific and research advancements, gaps in services and other emerging issues impacting this population and to determine if amendments are necessary.
    - (9) In consultation with the advisory committee, approving and implementing amendments to the State Plan.
  - (10) Identifying and managing grants to assist in the funding of the office, State Plan implementation and other programs and services to assist this Commonwealth in becoming dementia-capable.
- (11) In consultation with the advisory committee,

  compiling 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.

- 1 Section 4. Alzheimer's, Dementia and Related Disorders Advisory
- 2 Committee.
- 3 (a) Establishment.--The Alzheimer's, Dementia and Related
- 4 Disorders Advisory Committee is established in the department.
- 5 (b) Membership.--The advisory committee shall consist of the
- 6 following members:
- 7 (1) The secretary or a designee.
- 8 (2) The Secretary of Health or a designee.
- 9 (3) The Secretary of Human Services or a designee.
- 10 (4) The Secretary of Labor and Industry or a designee.
- 11 (5) The chair and minority chair of the Aging and Youth
- 12 Committee of the Senate or designees and the chair and
- minority chair of the Aging and Older Adult Services
- 14 Committee of the House of Representatives or designees.
- 15 (6) A member from the Pennsylvania Council on Aging.
- 16 (7) Bureau Director representing the Pharmaceutical
- 17 Assistance Contract for the Elderly program.
- 18 (8) An individual living with Alzheimer's, dementia or a
- 19 related disorder or a designee.
- 20 (9) A family member of or a caregiver for a person
- 21 living with Alzheimer's, dementia or a related disorder.
- 22 (10) An attorney with at least five years' experience in
- 23 providing legal representation to older adults with cognitive
- 24 diseases and related disorders.
- 25 (11) Three individuals from non-governmental Statewide
- organizations that advocate for older adults.
- 27 (12) A physician with at least five years' experience in
- diagnosing and treating Alzheimer's, dementia and related
- 29 disorders.
- 30 (13) Two individuals who conduct research regarding

- 1 Alzheimer's, dementia and related disorders.
- 2 (14) An individual representing the local area agencies
- 3 on aging.
- 4 (15) An individual representing the Commonwealth's
- 5 hospitals and health systems.
- 6 (16) An individual representing the facilities in the
- 7 Commonwealth that provide long-term care to individuals.
- 8 (17) An individual representing the Commonwealth's
- 9 community health centers in rural and urban communities.
- 10 (18) An individual representing older adult day living
- 11 centers.
- 12 (19) An individual representing the life providers.
- 13 (20) An individual representing a federally qualified
- 14 health center.
- 15 (21) An individual representing the Pennsylvania Society
- for Post-Acute and Long-Term Care Medicine.
- 17 (22) An individual representing a Statewide association
- dedicated to Alzheimer's care, support and research.
- 19 (c) Appointments.--Except for members under subsection (b)
- 20 (1), (2), (3), (4) and (5), members of the advisory committee
- 21 shall be appointed by the Governor to four-year staggered terms.
- 22 The members of the Governor's Cabinet and sitting members of the
- 23 Senate and the House of Representatives shall be appointed to a
- 24 term corresponding to the member's term of office.
- 25 (d) Term.--Members shall be eliqible for reappointment but
- 26 shall serve no more than two consecutive full terms. Members
- 27 shall serve until a successor is appointed and qualified,
- 28 provided the successor represents the interests of the
- 29 membership class for which the member was appointed.
- 30 (e) Vacancies. -- Any vacancy of the advisory committee shall

- 1 be filled by the original appointing authority. An individual
- 2 appointed to fill a vacancy shall serve the balance of the
- 3 previous member's term.
- 4 (f) Removal.--Members may be removed from the committee for
- 5 the following reasons:
- 6 (1) A member who fails to attend three consecutive
- 7 meetings shall forfeit the member's seat unless the
- 8 chairperson, upon written request from the member, finds that
- 9 the member should be excused from a meeting.
- 10 (2) A member shall forfeit the member's seat if the
- 11 member no longer represents the interests of the membership
- 12 class for which the member was appointed. A member meeting
- the threshold under this paragraph shall no longer be
- employed or associated with the interests of the respective
- qualifications for which the member was appointed.
- 16 (g) Expenses. -- Members may not receive compensation or
- 17 remuneration for service as advisory committee members.
- 18 Nongovernmental advisory committee members shall be entitled to
- 19 reimbursement for travel and related actual expenses accrued in
- 20 the performance of the duties as members, in accordance with
- 21 Commonwealth travel policy.
- 22 (h) Designee.--Governmental members and the member who is
- 23 living with Alzheimer's, dementia or related disorder may
- 24 appoint a designee to attend and vote at meetings of the
- 25 advisory committee. Each member who appoints a designee shall do
- 26 so by sending a letter to the chairperson stating the name of
- 27 the designee.
- 28 (i) Chair.--The chair of the advisory committee shall be the
- 29 secretary or a designee.
- 30 (j) Vice chair. -- The vice chair of the committee shall be

- 1 the Secretary of Health or a designee.
- 2 Section 5. Powers and duties of the advisory committee.
- 3 (a) Committee. -- The advisory committee shall meet on a
- 4 quarterly basis at minimum and shall have the following powers
- 5 and duties:
- 6 (1) Assess the current and future impact of Alzheimer's,
- dementia and related disorders on residents of this
- 8 Commonwealth.
- 9 (2) Examine the existing industries, services and
- 10 resources addressing the needs of persons with Alzheimer's,
- dementia and related disorders, their families and
- 12 caregivers.
- 13 (3) Develop strategies to mobilize a Statewide response
- to Alzheimer's, dementia and related disorders.
- 15 (4) Advise the department on necessary updates and
- implementation of the State Plan.
- 17 (5) Consult with various Commonwealth agencies and to
- 18 make recommendations on regulations, licensure, financing or
- any other responsibilities of those Commonwealth agencies
- relating to Alzheimer's, dementia and related disorders.
- 21 (6) Perform other duties as the Governor may assign
- relating to Alzheimer's, dementia and related disorders.
- 23 (7) Develop and adopt rules for conducting advisory
- committee meetings, including, but not limited to, the
- 25 procedure for formally adopting the approval of committee
- 26 reports before release to the public.
- 27 (b) Scope. -- All powers and duties enumerated in this section
- 28 shall be performed in a manner that addresses all areas of
- 29 Alzheimer's, dementia and related disorders.
- 30 Section 6. Effective date.

1 This act shall take effect in 180 days.