

[First Reprint]

ASSEMBLY, No. 4422

STATE OF NEW JERSEY

219th LEGISLATURE

INTRODUCED JULY 20, 2020

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SYNOPSIS

Establishes “Alzheimer’s and Dementia Care Long-Term Planning Commission” in DHS.

CURRENT VERSION OF TEXT

As reported by the Assembly Aging and Senior Services Committee on December 7, 2020, with amendments.

(Sponsorship Updated As Of: 12/2/2021)

1 AN ACT establishing a permanent Alzheimer's and Dementia Care
2 Long-Term Planning Commission, supplementing Title 26 of the
3 Revised Statutes, and repealing P.L.2011, c.76.

4
5 **BE IT ENACTED** by the Senate and General Assembly of the State
6 of New Jersey:

7
8 1. The Legislature finds and declares that:

9 a. Alzheimer's disease is a progressive, degenerative, and
10 irreversible neurological disease. It is one of a group of dementias
11 and related disorders that develop over a period of years, are of an
12 undetermined origin, and are characterized by a progressive decline
13 in intellectual or cognitive functioning that begins with gradual
14 short-term memory loss and progresses to include a deterioration in
15 all areas of cognition and executive functioning, such as analytical
16 ability and reasoning, language and communication, perception and
17 judgment, and personality, and that may eventually result in the
18 inability to perform physical functions, including, but not limited
19 to, the activities of daily life such as walking, dressing, feeding, and
20 bathing.

21 b. According to a *2020 Facts and Figures* report released by
22 the Alzheimer's Association, nearly six million Americans age 65
23 or older (one out of every 10 Americans in this age group) are
24 currently living with Alzheimer's disease. Barring the development
25 of medical breakthroughs to prevent, slow, or cure the disease, this
26 number is expected to rise to 7.1 million by 2025 (a 22 percent
27 increase) and to 13.8 million by 2050 (a 33 percent increase). In
28 New Jersey, the total number of seniors living with Alzheimer's
29 (190,000 in the year 2020) is expected to increase by more than 10
30 percent, to 210,000, by the year 2025.

31 c. Although the complexities of death reporting systems make
32 it difficult to accurately determine the total number of deaths that
33 have been directly or indirectly caused by Alzheimer's disease, the
34 Alzheimer's Association *2020 Facts and Figures* report estimated
35 the 2018 mortality rate for this disease to be 37.3 deaths for every
36 100,000 people nationwide and 30.4 deaths for every 100,000
37 people Statewide in New Jersey.

38 d. Alzheimer's disease progresses in a gradual and insidious
39 manner. While most persons with dementia live eight to 10 years
40 after receiving their diagnosis, some can live as long as 20 years as
41 they continue to lose their ability to function. As of 2016,
42 Alzheimer's disease was ranked as the sixth most burdensome
43 disease in the nation in terms of total disability-adjusted life years
44 (DALYs) and the fourth most burdensome disease in terms of the
45 total number of years of life that are lived with a disability (YLDs).

EXPLANATION – Matter enclosed in bold-faced brackets **[thus]** in the above bill is
not enacted and is intended to be omitted in the law.

Matter underlined thus is new matter.

Matter enclosed in superscript numerals has been adopted as follows:

¹Assembly ASE committee amendments adopted December 7, 2020.

1 e. In addition to burdening the person who suffers from the
2 disease, Alzheimer's disease and related dementias place a
3 tremendous and years-long burden on caregivers, particularly
4 family or other unpaid caregivers. These caregivers often assist
5 persons with Alzheimer's disease in performing one or more
6 activities of daily living, including bathing, dressing, paying bills,
7 shopping, and navigating transportation systems. Caregivers also
8 provide extensive emotional support and engage in a variety of
9 other ancillary tasks, such as communicating and coordinating the
10 care needs of the individual with Alzheimer's, ensuring the
11 individual's safety at home and elsewhere, and managing the
12 individual's other health conditions. Caring for a person with
13 Alzheimer's disease or related dementias poses unique challenges,
14 and caregivers are often required to manage the patient's
15 personality and behavioral changes for decades and provide
16 increasing levels of supervision and personal care as the disease
17 progresses. As symptoms worsen, the increase in caregiving
18 obligations can cause emotional stress and depression and new or
19 exacerbated health problems in the caregiver, as well as depleted
20 income due, in part, to disruptions in the caregiver's employment
21 and the need for the caregiver to finance the health care or other
22 services received by the person with Alzheimer's disease or other
23 dementia.

24 f. In 2019, more than 16 million caregivers provided an
25 estimated 18.6 billion hours in unpaid assistance across the nation
26 to persons with Alzheimer's disease or other dementias – a
27 contribution to the nation that is valued at \$244 billion (or 11 times
28 the total revenue of McDonald's in 2018). This included 448
29 caregivers who provided 510 million hours (or \$6.6 billion worth)
30 of unpaid care in New Jersey alone.

31 g. Although personal care professionals, certified nurse aides,
32 homemaker-home health aides, and other direct care professionals
33 may be capable of providing paid caregiving services to persons
34 with Alzheimer's disease and related dementias, because of the low
35 pay in this area and the tireless, difficult, and thankless nature of the
36 work, there is currently a significant shortage of these professionals
37 in the State, and turnover rates are high.

38 h. In addition to causing significant physical and mental
39 burdens both to individuals who have the disease and to their
40 caregivers, dementia, including Alzheimer's, is one of the costliest
41 conditions to society. In 2020, the total nationwide cost of caring
42 for persons with Alzheimer's and other dementias is projected to
43 reach \$305 billion (not including \$244 billion in unpaid caregiver
44 costs). While Medicaid and Medicare are expected to cover \$206
45 billion (67 percent) of the total costs of dementia-related care, out-
46 of-pocket spending is expected to amount to \$66 billion in 2020
47 alone (22 percent of total payments).

1 i. In 2019, total per-person health care and long-term care
2 payments from all sources for Medicare beneficiaries with
3 Alzheimer's or other dementias were over three times as great as
4 payments for other Medicare beneficiaries in the same age group
5 (\$50,201 per person for those with dementia compared with
6 \$14,326 per person for those without dementia).

7 j. In New Jersey, it is expected that total Medicaid payments
8 for persons age 65 and older who are living with Alzheimer's will
9 amount to nearly \$2.2 billion in 2020 and will increase more than
10 19 percent to \$2.6 billion by 2025.

11 k. The total lifetime cost of care for someone with Alzheimer's
12 or other dementias was estimated to be \$357,297 in 2019.
13 According to the Alzheimer's Association *2020 Facts and Figures*
14 report, 70 percent of this lifetime cost of care is borne by family
15 caregivers in the form of unpaid caregiving and payments for out-
16 of-pocket expenses. These lifetime cost estimates, moreover, likely
17 underestimate the financial impacts that a person's dementia has on
18 the health and workplace productivity levels of the person's family
19 caregiver.

20 l. Persons with dementia are also more likely than others to
21 have co-occurring health care conditions. Of persons with
22 Alzheimer's disease and other dementias, 38 percent also have
23 coronary artery disease, 37 percent have diabetes, 29 percent have
24 chronic kidney disease, 28 percent have congestive heart failure, 25
25 percent have chronic obstructive pulmonary disease, 22 percent
26 have stroke-related care, and 13 percent have cancer. Medicare
27 beneficiaries with Alzheimer's or other dementias have higher rates
28 of hospitalization than other patients for all of these co-occurring
29 conditions and higher average per-person payments in all categories
30 except in the case of hospital care payments for individuals with
31 congestive heart failure.

32 m. In general, patients with Alzheimer's or other dementias
33 have a 30 percent greater risk than other patients of experiencing a
34 preventable hospitalization event, and patients with both dementia
35 and depression have a 70 percent greater risk of preventable
36 hospitalization than persons without a neuropsychiatric disorder.

37 n. There is currently a shortage of specialized geriatric
38 professionals in the State and nation to meet the needs of the rapidly
39 growing aging population and the complex needs of aging
40 individuals who are living with Alzheimer's disease and related
41 dementias. The Alzheimer's Association *2020 Facts and Figures*
42 report estimates that, by 2030, an additional 23,750 geriatricians
43 will be needed to meet the needs of the aging population
44 nationwide. In New Jersey, moreover, the shortage of geriatricians
45 is particularly great. As of 2019, the State had only 205
46 geriatricians. The *2020 Facts and Figures* report indicates that, by
47 2050, the State will need at least 398 geriatricians to serve a mere
48 10 percent of the population aged 65 years or older and will require

1 a nearly six-fold increase in geriatricians (or a total of 1,193
2 geriatricians) to serve 30 percent of the population in this age
3 group.

4 o. With a significant shortage of geriatric specialists to meet
5 current and future dementia care needs, primary care physicians
6 (PCPs) will play an increasingly important role in caring for
7 dementia patients along the continuum of the disease and should,
8 therefore, be properly trained in identifying the warning signs of
9 Alzheimer's disease and related dementias, providing timely and
10 competent dementia diagnoses, and meeting the ongoing care and
11 support needs of patients who are living with dementia.

12 p. While 82 percent of the 1,000 PCPs surveyed for the 2020
13 *Facts and Figures* report indicated that they are already working on
14 the front lines of Alzheimer's care, half reported that the medical
15 profession is not adequately prepared to meet increased demand in
16 this area. These PCPs also reported a lack of access to sufficient
17 dementia-related training in medical schools and residency
18 programs, and more than half indicated that they had not pursued
19 additional training in dementia care following graduation or
20 residency, due to challenges associated with obtaining such
21 supplemental training.

22 q. Although the State has previously attempted to identify and
23 address issues associated with Alzheimer's disease and related
24 dementias through the enactment of P.L.1983, c.352 (C.26:2M-1 et
25 seq.) and P.L.2011, c.76 (C.26:2M-16 et seq.) and the establishment
26 of two different study commissions thereunder, each of those study
27 commissions was temporary in nature and dissolved after the
28 submission of a single report.

29 r. In light of the severe ongoing and worsening impacts and
30 burdens of Alzheimer's disease and related dementias, the
31 projections for rapid increases in the number of persons presenting
32 with these conditions into the future, and New Jersey's current lack
33 of a robust professional workforce necessary to address the
34 concerns of this growing population of patients and their families, it
35 is both reasonable and necessary for the State to establish a
36 permanent commission to engage in a concerted, proactive, and
37 ongoing effort to study and develop innovative solutions to address
38 and mitigate the effects of this disease on citizens of this State, both
39 now and into the future.

40

41 2. a. The Alzheimer's and Dementia Care Long-Term
42 Planning Commission is established in the Department of Human
43 Services. The purpose of the commission shall be to provide for the
44 ongoing evaluation of the State's Alzheimer's disease and dementia
45 care system and identify various innovative means and methods that
46 can be used to address the significant shortcomings in that care
47 system and otherwise expand and prepare the system to meet the
48 increasing and evolving needs of a rapidly aging population.

1 b. The commission shall consist of '~~31~~12' members,
2 including:

3 (1) 'Three non-voting ex officio members or their designees as
4 follows:' the Commissioner of Health, the Commissioner of
5 Human Services, 'and' the New Jersey Long Term Care
6 Ombudsman '~~1~~', the Director of the Division of Aging Services in
7 the Department of Human Services, the Director of the Office of the
8 Public Guardian for the Elderly in the Department of Human
9 Services, the Director of the Office of Minority and Multicultural
10 Health in the Department of Health, the Director of the Division of
11 Medical Assistance and Health Services in the Department of
12 Human Services, the President of Alzheimer's New Jersey, the
13 Executive Director of the Alzheimer's Association Greater New
14 Jersey Chapter, the Executive Director of the Alzheimer's
15 Association Delaware Valley Chapter, the President of the New
16 Jersey Health Care Quality Institute, the President of the Home
17 Care and Hospice Association of New Jersey, the President of the
18 New Jersey Hospital Association, the President of LeadingAge New
19 Jersey, the Executive Director of Caregivers of New Jersey, the
20 President of the New Jersey chapter of the AARP, and the
21 Executive Director of the National Alliance on Mental Illness in
22 New Jersey, or their designees, who shall serve ex officio '~~1~~';

23 (2) two 'public' members 'to be appointed by the President' of
24 the Senate '~~1~~' who are not of the same political party, one of whom
25 shall be appointed by the President of the Senate and one of whom
26 shall be appointed by the Senate Minority Leader '~~1~~' as follows: one
27 who shall represent an organization that advocates for members of
28 the Alzheimer's community and one who shall represent a for-profit
29 healthcare facility that offers memory care services '~~1~~';

30 (3) two 'public' members 'to be appointed by the Speaker' of
31 the General Assembly '~~1~~' who are not of the same political party, one
32 of whom shall be appointed by the Speaker of the General
33 Assembly and one of whom shall be appointed by the Minority
34 Leader of the General Assembly '~~1~~' as follows: one who shall
35 represent an organization that advocates for members of the
36 Alzheimer's community and one who shall represent a non-profit
37 healthcare facility that offers memory care services '~~1~~'; and

38 (4) '~~10~~ five' public members to be appointed by the Governor
39 as follows: '~~1~~' two health care professionals one geriatrician '~~1~~' who
40 '~~are~~ shall' currently 'be' involved in the provision of direct
41 services to patients with Alzheimer's disease or other related
42 dementias '~~1~~', one of whom shall be a geriatric specialist and one of
43 whom shall be a primary care physician '~~1~~'; '~~1~~' two mental health care
44 professionals one psychiatrist '~~1~~' who 'shall' provide specialized
45 services to persons with Alzheimer's disease or related
46 dementias '~~1~~', at least one of whom shall be a psychiatrist '~~1~~'; one

1 'personal care assistant, one homemaker-home health aide, and
2 one certified nurse aide, each of whom provides] caregiver who
3 shall provide¹ paid services to persons with Alzheimer's disease or
4 related dementias; one 'citizen who is an]' unpaid caregiver of a
5 family member who has Alzheimer's disease or a related
6 dementia;¹and¹ one 'citizen] neurologist¹ who 'is an unpaid
7 caregiver of a family member who has both] provides specialized
8 services to persons with¹ Alzheimer's disease or a related dementia
9 'and at least one other significant co-occurring disease, disorder,
10 or condition; and one senior citizen 65 years of age or older. Of the
11 public members appointed to the commission, not more than five
12 shall be of the same political party]¹.

13 c. Each public member of the commission shall serve for a
14 term of four years; however, of the public members first appointed,
15 two shall serve an initial term of one year, three shall serve an
16 initial term of two years, '[three]two¹ shall serve an initial term of
17 three years, and two shall serve an initial term of four years. Each
18 public member shall serve for the term of their appointment and
19 until a successor is appointed and qualified, except that a public
20 member may be reappointed to the commission upon the expiration
21 of their term.

22 d. All initial appointments to the commission shall be made
23 within 60 days after the effective date of this act. Vacancies in the
24 membership of the commission shall be filled in the same manner
25 provided for the original appointments.

26 e. Any member of the commission may be removed by the
27 Governor, for cause, after a public hearing.

28 f. The commission shall organize as soon as practicable, but
29 not later than the 30th day, following the appointment of a majority
30 of its members and shall annually elect a chairperson and vice-
31 chairperson from among its members. The chairperson shall
32 appoint a secretary, who need not be a member of the commission.

33 g. Each year, the commission shall meet pursuant to a schedule
34 to be established at its first annual meeting. The commission shall
35 additionally meet at the call of its chairperson or the Commissioners
36 of Health or Human Services. In no case shall the commission meet
37 less than four times per year.

38 h. A majority of the total number of members currently
39 appointed to the commission shall constitute a quorum. A vacancy
40 in the membership of the commission shall not impair the ability of
41 the commission to exercise its duties and effectuate its purposes.
42 The commission may conduct business without a quorum, but may
43 only vote on recommendations when a quorum is present.
44 Recommendations shall be approved by a majority of the members
45 present.

46 i. The members of the commission shall serve without
47 compensation, but shall be reimbursed for travel and other

1 miscellaneous expenses incurred in the necessary performance of
2 their duties, within the limits of funds made available to the
3 commission for its purposes.

4 j. The commission shall have the power to:

5 (1) adopt, amend, or repeal suitable bylaws for the management
6 of its affairs;

7 (2) maintain an office at such place or places as it shall
8 designate;

9 (3) solicit, receive, accept, and expend any grant moneys or
10 other funds that may be made available for its purposes by any
11 government agency or any private for-profit or not-for-profit
12 organization or entity;

13 (4) solicit and receive assistance and services from any State,
14 county, or municipal department, board, commission, or agency, as
15 it may require, and as may be available to it for its purposes;

16 (5) enter into any and all agreements or contracts, execute any
17 and all instruments, and do and perform any and all acts or things
18 necessary, convenient, or desirable to further the commission's
19 purposes; and

20 (6) consult with, and solicit and receive testimony from, any
21 association, organization, department, agency, or individual having
22 knowledge of, and experience with: (a) the treatment and care of,
23 or provision of caregiving and personal care services to, persons
24 with Alzheimer's disease and other dementias; (b) the status or
25 quality of the State's professional workforce in relation to
26 Alzheimer's disease and dementia care; (c) the emotional, physical,
27 or financial effects of Alzheimer's disease and other dementias on
28 individuals, families, and the State; or (d) any other issues related to
29 Alzheimer's disease or dementia.

30 k. The Department of Human Services shall provide
31 professional and clerical staff to the commission, as may be
32 necessary to effectuate the purposes of this act.

33

34 3. a. The Alzheimer's and Dementia Care Long-Term
35 Planning Commission, established pursuant to this act, shall have
36 the ongoing duty to:

37 (1) study the incidence, prevalence, and impact of Alzheimer's
38 disease and related dementias in the State and in each region of the
39 State and make projections about the future Statewide and regional
40 incidence, prevalence, and impact of these conditions;

41 (2) gather, analyze, and disseminate to health care professionals,
42 policymakers, and members of the public, as appropriate, data and
43 information about: (a) the needs of persons with Alzheimer's
44 disease and related dementias, as well as the needs of their family
45 members and caregivers; (b) the quality and consistency of care that
46 is provided to persons¹, including those members of the medically
47 underserved, poor, and lesbian, gay, bisexual, transgender,
48 questioning, queer, and intersex (LGBTQI) communities,¹ with

1 Alzheimer's disease and related dementias in the State; (c) the
2 affordability of Alzheimer's and dementia care in the State and the
3 actual and projected Statewide costs and individual costs associated
4 with Alzheimer's disease and related dementias in New Jersey,
5 including, but not limited to, the costs of health care, mental health
6 care, long-term care, and personal care, and ancillary or incidental
7 costs such as those associated with the lost work productivity of, or
8 the treatment of stress-related physical conditions or depression and
9 other mental health conditions in, family caregivers; (d) the cost-
10 savings attained by the State through the provision of unpaid
11 caregiving and personal care services by family caregivers; (e) the
12 capacity of the State's health care and long-term care facilities to
13 house and provide specialized services to persons with Alzheimer's
14 or related dementias; (f) the status of Alzheimer's and dementia
15 care in other states, as compared to New Jersey; and (g) any other
16 issue deemed by the commission to be relevant to effectuate the
17 purposes of this act;

18 (3) assess the availability and affordability of existing programs,
19 services, facilities, and agencies in the State that are used to meet
20 the needs of persons with Alzheimer's disease or other dementias
21 and the needs of their families and caregivers; evaluate the capacity
22 of those existing policies, programs, services, facilities, and
23 agencies to adapt to and adequately address the changing needs of
24 dementia patients and their families and caregivers in the face of a
25 continually increasing demand for services; and identify and
26 recommend improvements to existing policies, programs, services,
27 facilities, or agencies or the institution of new policies, programs,
28 services, facilities, or agencies to address unmet and expanding
29 needs in this area;

30 (4) study and outline the appropriate roles of State government,
31 local governments, and health care facilities and professionals in
32 providing or ensuring the provision of appropriate services and
33 other assistance to persons with Alzheimer's disease or related
34 dementias, including persons in early stages of disease, and in
35 providing or ensuring the provision of sufficient supportive and
36 assistive services, including training and respite services, to unpaid
37 family caregivers; and identify ways in which State and local
38 governments and health care systems could increase their awareness
39 of, and improve their ability to more effectively address, issues
40 affecting persons with Alzheimer's disease or other dementias and
41 their families;

42 (5) review and analyze the capacity of law enforcement officers
43 and emergency medical responders in the State to compassionately
44 and effectively interact with, diffuse conflicts involving, and
45 provide emergency services to, persons with Alzheimer's disease
46 and related dementias;

47 (6) identify and recommend best practices and training
48 requirements for: (a) health care and mental health care

1 professionals, particularly geriatric specialists and primary care
2 practitioners, who are or will be practicing on the front lines of
3 Alzheimer's and dementia care, in order to ensure that such
4 professionals are properly trained and are capable of accurately and
5 timely diagnosing Alzheimer's disease and related dementias,
6 understanding the progression of the disease, and recognizing and
7 responding to the evolving needs of patients; (b) personal care
8 professionals who provide services to patients with Alzheimer's
9 disease or related dementias, in order to ensure that such
10 professionals are capable of providing compassionate and high
11 quality personal care services and adapting to the evolving needs of
12 their patients; and (c) law enforcement officers, emergency medical
13 responders, and other public safety officers, in order to ensure that
14 those officers understand the complexities of dealing with persons
15 with Alzheimer's disease and other dementias and are better
16 prepared to compassionately diffuse or resolve conflicts and
17 respond to emergencies involving such persons;

18 (7) evaluate the sufficiency of the State's Alzheimer's and
19 dementia care workforce, identify current and future workforce
20 needs, anticipate future workforce shortages, develop innovative
21 strategies to encourage and increase the recruitment and retention of
22 health care, mental health care, direct support, and personal care
23 professionals who are trained to provide Alzheimer's and dementia
24 care, and take any other action necessary to encourage and facilitate
25 the development and maintenance of a robust and specialized
26 professional Statewide workforce that is capable of delivering high
27 quality Alzheimer's and dementia-related care to a rapidly growing
28 population in the State; and

29 (8) study and make recommendations on any other issue related
30 to Alzheimer's disease or other dementias.

31 b. One year after the commission's organizational meeting, and
32 annually thereafter, the commission shall prepare and submit a
33 written report to the Governor and, pursuant to section 2 of
34 P.L.1991, c.164 (C.52:14-19.1), to the Legislature. The written
35 report shall contain, at a minimum:

36 (1) the commission's annual findings on the issues described in
37 subsection a. of this section;

38 (2) a description as to whether, how, and why the commission's
39 findings have changed over time, including an indication as to the
40 implementation status of the commission's prior recommendations,
41 a description of actions that have been undertaken by any person or
42 public or private entity in the State over the prior reporting period
43 to implement those prior recommendations, and a description of the
44 perceived or documented effects resulting from implementation of
45 those prior recommendations;

46 (3) a copy of, or reference to, the statistical, demographic,
47 testimonial, or other data or information that was used by the
48 commission to: (a) support its current findings under paragraph (1)

- 1 of this subsection; or (b) inform its analysis of the impact of the
2 commission's prior recommendations under paragraph (2) of this
3 subsection. The data provided pursuant to this paragraph shall be
4 presented in aggregate form and shall not contain the personally
5 identifying information of any patient, caregiver, or other person;
6 and
- 7 (4) the commission's recommendations for legislative,
8 executive, or other actions that can be undertaken, or strategies that
9 can be implemented, to: (a) improve the quality, consistency, or
10 affordability of Alzheimer's and dementia care in the State and
11 ensure its accessibility to all who need it; (b) reduce, eliminate, or
12 mitigate the societal and individual impact of, and the Statewide,
13 local, and individual costs or financial burdens associated with,
14 Alzheimer's disease and other dementias; (c) ensure that the State's
15 professional workforce is adequately trained, is capable of
16 providing affordable, high quality Alzheimer's and dementia care
17 throughout the State, and is sufficient in numbers and flexible
18 enough to adapt to a rapidly increasing demand for services in the
19 State; (d) ensure that unpaid caregivers in the State are recognized
20 for their dedicated service and significant contributions to society
21 and are provided with sufficient supportive and respite services, as
22 well as financial assistance where possible and appropriate, as may
23 be necessary for them to capably perform their caregiving tasks
24 while avoiding unnecessary physical, mental, or financial strain; or
25 (e) otherwise address the issues or mitigate the problems identified
26 by the commission in its annual findings.
- 27
- 28 4. P.L.2011, c.76 (C.26:2M-16 et seq.) is repealed.
- 29
- 30 5. This act shall take effect immediately.