## [First Reprint] SENATE, No. 2796

# STATE OF NEW JERSEY 219th LEGISLATURE

INTRODUCED AUGUST 3, 2020

Sponsored by: Senator JOSEPH F. VITALE District 19 (Middlesex) Senator RICHARD J. CODEY District 27 (Essex and Morris)

Co-Sponsored by: Senators Diegnan, Pou, Holzapfel and O'Scanlon

#### SYNOPSIS

Establishes "Alzheimer's and Dementia Care Long-Term Planning Commission" in DHS.

#### **CURRENT VERSION OF TEXT**

As reported by the Senate Health, Human Services and Senior Citizens Committee on February 9, 2021, with amendments.



(Sponsorship Updated As Of: 11/8/2021)

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

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

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

20 b. According to a 2020 Facts and Figures report released by the 21 Alzheimer's Association, nearly six million Americans age 65 or older 22 <sup>1</sup>[(one], <u>or one</u><sup>1</sup> out of every 10 Americans in this age <sup>1</sup>[group)] group,<sup>1</sup> are currently living with Alzheimer's disease. Barring the 23 development of medical breakthroughs to prevent, slow, or cure the 24 disease, this number is expected to rise  ${}^{1}\underline{by} a factor of 22 percent^{1}$  to 25 7.1 million by 2025 <sup>1</sup>[(a 22 percent increase)],<sup>1</sup> and <sup>1</sup>to increase by a 26 factor of 33 percent<sup>1</sup> to 13.8 million by 2050 <sup>1</sup>[(a 33 percent 27 increase)]<sup>1</sup>. In New Jersey, the total number of seniors living with 28 Alzheimer's <sup>1</sup>[(190,000 in the year 2020)], which was 190,000 in the 29 year  $2020^{1}$  is expected to increase by more than 10 percent, to 30 31 210,000, by the year 2025.

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

d. Alzheimer's disease progresses in a gradual and insidious
manner. While most persons with dementia live eight to 10 years after
receiving their diagnosis, some can live as long as 20 years as they
continue to lose their ability to function. As of 2016, Alzheimer's
disease was ranked as the sixth most burdensome disease in the nation
in terms of total disability-adjusted life years <sup>1</sup>[(DALYs)]<sup>1</sup> and the

**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 <u>thus</u> is new matter.

Matter enclosed in superscript numerals has been adopted as follows: <sup>1</sup>Senate SHH committee amendments adopted February 9, 2021. fourth most burdensome disease in terms of the total number of years
of life that are lived with a disability <sup>1</sup>[(YLDs)]<sup>1</sup>.

e. In addition to burdening the person who suffers from the 3 disease, Alzheimer's disease and related <sup>1</sup>[dementias] disorders or 4 5 other forms of dementia<sup>1</sup> place a tremendous and years-long burden on caregivers, particularly family or other unpaid caregivers. 6 These 7 caregivers often assist persons with Alzheimer's disease in performing 8 one or more activities of daily living, including bathing, dressing, 9 paying bills, shopping, and navigating transportation systems. 10 Caregivers also provide extensive emotional support and engage in a 11 variety of other ancillary tasks, such as communicating and 12 coordinating the care needs of the individual with Alzheimer's, 13 ensuring the individual's safety at home and elsewhere, and managing 14 the individual's other health conditions. Caring for a person with 15 Alzheimer's disease or related dementias poses unique challenges, and 16 caregivers are often required to manage the patient's personality and 17 behavioral changes for decades and provide increasing levels of 18 supervision and personal care as the disease progresses. As symptoms 19 worsen, the increase in caregiving obligations can cause emotional 20 stress and depression and new or exacerbated health problems in the 21 caregiver, as well as depleted income due, in part, to disruptions in the 22 caregiver's employment and the need for the caregiver to finance the 23 health care or other services received by the person with Alzheimer's disease <sup>1</sup>[or] and related disorders or <sup>1</sup> other <sup>1</sup>forms of <sup>1</sup> dementia. 24

f. In 2019, more than 16 million caregivers provided an estimated 25 26 18.6 billion hours in unpaid assistance across the nation to persons 27 with Alzheimer's disease <sup>1</sup>and related disorders<sup>1</sup> or other <sup>1</sup>[dementias] forms of dementia<sup>1</sup> – a contribution to the nation that is 28 valued at \$244 billion <sup>1</sup>[(or], which is equal to approximately<sup>1</sup> 11 29 times the total revenue of McDonald's in  ${}^{1}$ [2018)] <u>2018</u><sup>1</sup>. This 30 included 448 caregivers who provided 510 million hours <sup>1</sup>[(or \$6.6 31 billion worth)] equal to \$6.6 billion worth<sup>1</sup> of unpaid care in New 32 33 Jersey alone.

34 g. Although personal care professionals, certified nurse aides, 35 homemaker-home health aides, and other direct care professionals may be capable of providing paid caregiving services to persons with 36 37 Alzheimer's disease and related <sup>1</sup>[dementias] <u>disorders or other</u> forms of dementia<sup>1</sup>, because of the low pay <sup>1</sup>[in this area] for 38 caregiving services<sup>1</sup> and the tireless, difficult, and thankless nature of 39 the work, there is currently a significant shortage of these 40 professionals in the State, and turnover rates are high. 41

h. In addition to causing significant physical and mental burdens
both to individuals who have the disease and to their caregivers,
dementia, including Alzheimer's, is one of the costliest conditions to
society. In 2020, the total nationwide cost of caring for persons with
Alzheimer's <sup>1</sup>disease<sup>1</sup> and <sup>1</sup>related disorders or<sup>1</sup> other <sup>1</sup>[dementias]

forms of dementia<sup>1</sup> is projected to reach \$305 billion <sup>1</sup>[(not], not<sup>1</sup> including \$244 billion in unpaid caregiver <sup>1</sup>[costs)] costs<sup>1</sup>. <sup>1</sup>[While] <u>Although<sup>1</sup> Medicaid and Medicare are expected to cover \$206 billion</u> <sup>1</sup>[(67 percent)] or 67 percent<sup>1</sup> of the total costs of dementia-related care, out-of-pocket spending is expected to amount to \$66 billion in 2020 alone <sup>1</sup>[(22], which is equal to 22<sup>1</sup> percent of total <sup>1</sup>[payments)] payments under the programs<sup>1</sup>.

i. In 2019, total per-person health care and long-term care 8 9 payments from all sources for Medicare beneficiaries with Alzheimer's <sup>1</sup>disease and related disorders<sup>1</sup> or other <sup>1</sup>[dementias] 10 forms of dementia<sup>1</sup> were <sup>1</sup>\$50,201 per person for those with dementia 11 and \$14,326 person for those without dementia, which is<sup>1</sup> over three 12 13 times as great as payments for other Medicare beneficiaries in the 14 same age group <sup>1</sup>[(\$50,201 per person for those with dementia 15 compared with \$14,326 per person for those without dementia)  $]^1$ .

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

20 k. The total lifetime cost of care for someone with Alzheimer's <sup>1</sup><u>disease and related disorders</u><sup>1</sup> or other <sup>1</sup>[dementias] <u>forms of</u> 21 dementia<sup>1</sup> was estimated to be \$357,297 in 2019. According to the 22 23 Alzheimer's Association 2020 Facts and Figures report, 70 percent of 24 this lifetime cost of care is borne by family caregivers in the form of 25 unpaid caregiving and payments for out-of-pocket expenses. These 26 lifetime cost estimates, moreover, likely underestimate the financial 27 impacts that a person's dementia has on the health and workplace 28 productivity levels of the person's family caregiver.

29 1. Persons with dementia are also more likely than others to have 30 co-occurring health care conditions. Of persons with Alzheimer's disease and <sup>1</sup>related disorders or<sup>1</sup> other <sup>1</sup>[dementias] forms of 31 dementia<sup>1</sup>, 38 percent also have coronary artery disease, 37 percent 32 33 have diabetes, 29 percent have chronic kidney disease, 28 percent have 34 congestive heart failure, 25 percent have chronic obstructive 35 pulmonary disease, 22 percent have stroke-related care, and 13 percent 36 have cancer. Medicare beneficiaries with Alzheimer's <sup>1</sup>disease and related disorders<sup>1</sup> or other <sup>1</sup>[dementias] forms of dementia<sup>1</sup> have 37 higher rates of hospitalization than other patients for all of these co-38 39 occurring conditions and higher average per-person payments in all 40 categories except in the case of hospital care payments for individuals 41 with congestive heart failure.

m. In general, patients with Alzheimer's <sup>1</sup>disease and related
disorders<sup>1</sup> or other <sup>1</sup>[dementias] forms of dementia<sup>1</sup> have a 30 percent
greater risk than other patients of experiencing a preventable
hospitalization event, and patients with both dementia and depression

have a 70 percent greater risk of preventable hospitalization than
 persons without a neuropsychiatric disorder.

3 n. There is currently a shortage of specialized geriatric professionals in the State and nation to meet the needs of the rapidly 4 5 growing <sup>1</sup>[aging] population of individuals aged 65 years or older<sup>1</sup> and the complex needs of aging individuals who are living with 6 7 Alzheimer's disease and related <sup>1</sup>[dementias] disorders or other 8 forms of dementia<sup>1</sup>. The Alzheimer's Association 2020 Facts and 9 Figures report estimates that, by 2030, an additional 23,750 10 geriatricians will be needed to meet the needs of the aging population 11 nationwide. In New Jersey, moreover, the shortage of geriatricians is 12 particularly great. As of 2019, the State had only 205 geriatricians. 13 The 2020 Facts and Figures report indicates that, by 2050, the State 14 will need at least 398 geriatricians to serve a mere 10 percent of the population aged 65 years or older and will require a <sup>1</sup>total of 1,193 15 geriatricians, representing  $a^1$  nearly six-fold increase <sup>1</sup>[in geriatricians 16 17 (or a total of 1,193 geriatricians)]<sup>1</sup> to serve 30 percent of the 18 population in this age group.

19 o. With a significant shortage of geriatric specialists to meet 20 current and future dementia care needs, primary care physicians 21 (PCPs) will play an increasingly important role in caring for dementia 22 patients along the continuum of the disease and should, therefore, be 23 properly trained in identifying the warning signs of Alzheimer's disease and related <sup>1</sup>[dementias] <u>disorders or other forms of</u> 24 dementia<sup>1</sup>, providing timely and competent dementia diagnoses, and 25 26 meeting the ongoing care and support needs of patients who are living 27 with dementia.

28 p. <sup>1</sup>[While] <u>Although</u><sup>1</sup> 82 percent of the 1,000 PCPs surveyed 29 for the 2020 Facts and Figures report indicated that they are already 30 working on the front lines of Alzheimer's care, half reported that the 31 medical profession is not adequately prepared to meet increased 32 demand in this area. These PCPs also reported a lack of access to 33 sufficient dementia-related training in medical schools and residency 34 programs, and more than half indicated that they had not pursued 35 additional training in dementia care following graduation or residency, 36 due to challenges associated with obtaining such supplemental 37 training.

38 q. Although the State has previously attempted to identify and 39 address issues associated with Alzheimer's disease and related <sup>1</sup>[dementias] <u>disorders or other forms of dementia</u><sup>1</sup> through the 40 41 enactment of P.L.1983, c.352 (C.26:2M-1 et seq.) and P.L.2011, c.76 42 (C.26:2M-16 et seq.) and the establishment of two different study commissions thereunder, each of those study commissions was 43 44 temporary in nature and dissolved after the submission of a single 45 report.

46 r. In light of the severe ongoing and worsening impacts and
47 burdens of Alzheimer's disease and related <sup>1</sup>[dementias] <u>disorders or</u>

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1 other forms of dementia<sup>1</sup>, the projections for rapid increases in the 2 number of persons presenting with these conditions into the future, and 3 New Jersey's current lack of a robust professional workforce 4 necessary to address the concerns of this growing population of 5 patients and their families, it is both reasonable and necessary for the 6 State to establish a permanent commission to engage in a concerted, 7 proactive, and ongoing effort to study and develop innovative 8 solutions to address and mitigate the effects of this disease on citizens 9 of this State, both now and into the future.

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11 2. a. The Alzheimer's and Dementia Care Long-Term Planning 12 Commission is established in the Department of Human Services. The 13 purpose of the commission shall be to provide for the ongoing 14 evaluation of the State's Alzheimer's disease and dementia care 15 system and identify various innovative means and methods that can be 16 used to address the significant shortcomings in that care system and 17 otherwise expand and prepare the system to meet the increasing and 18 evolving needs of a rapidly aging population.

b. The commission shall consist of <sup>1</sup>[31] <u>12</u><sup>1</sup> members,
including:

(1) <sup>1</sup><u>Three non-voting ex officio members or their designees as</u> 21 the Commissioner of Health, the Commissioner of 22 follows:<sup>1</sup> Human Services, <sup>1</sup>and<sup>1</sup> the New Jersey Long Term Care 23 Ombudsman <sup>1</sup>[, the Director of the Division of Aging Services in 24 25 the Department of Human Services, the Director of the Office of the 26 Public Guardian for the Elderly in the Department of Human 27 Services, the Director of the Office of Minority and Multicultural 28 Health in the Department of Health, the Director of the Division of 29 Medical Assistance and Health Services in the Department of 30 Human Services, the President of Alzheimer's New Jersey, the 31 Executive Director of the Alzheimer's Association Greater New 32 Jersey Chapter, the Executive Director of the Alzheimer's 33 Association Delaware Valley Chapter, the President of the New 34 Jersey Health Care Quality Institute, the President of the Home 35 Care and Hospice Association of New Jersey, the President of the New Jersey Hospital Association, the President of LeadingAge New 36 37 Jersey, the Executive Director of Caregivers of New Jersey, the President of the New Jersey chapter of the AARP, and the 38 39 Executive Director of the National Alliance on Mental Illness in 40 New Jersey, or their designees, who shall serve ex officio  $\mathbf{J}^1$ ;

(2) two <sup>1</sup>public<sup>1</sup> members <sup>1</sup>to be appointed by the President<sup>1</sup> of the
Senate <sup>1</sup>[who are not of the same political party, one of whom shall be
appointed by the President of the Senate and one of whom shall be
appointed by the Senate Minority Leader] as follows: one who shall
represent an organization that advocates for members of the
Alzheimer's community and one who shall represent a for-profit
healthcare facility that offers memory care services<sup>1</sup>;

(3) two <sup>1</sup><u>public</u><sup>1</sup> members <sup>1</sup><u>to be appointed by the Speaker</u><sup>1</sup> of 1 2 the General Assembly <sup>1</sup>[who are not of the same political party, one 3 of whom shall be appointed by the Speaker of the General 4 Assembly and one of whom shall be appointed by the Minority 5 Leader of the General Assembly as follows: one who shall 6 represent an organization that advocates for members of the 7 Alzheimer's community and one who shall represent a non-profit healthcare facility that offers memory care services<sup>1</sup>; and 8

(4)  ${}^{1}$  [10] <u>five</u><sup>1</sup> public members to be appointed by the Governor 9 as follows: <sup>1</sup>[two health care professionals] <u>one geriatician</u><sup>1</sup> who 10 <sup>1</sup>[are]  $\underline{is}^{1}$  currently involved in the provision of direct services to 11 12 patients with Alzheimer's disease <sup>1</sup>[or other related dementias, one 13 of whom shall be a geriatric specialist and one of whom shall be a 14 primary care physician] and related disorders or other forms of dementia<sup>1</sup>; <sup>1</sup>[two mental health care professionals] <u>one</u> 15 <u>psychiatrist</u><sup>1</sup> who <sup>1</sup>[provide] <u>provides</u><sup>1</sup> specialized services to 16 17 persons with Alzheimer's disease <sup>1</sup>[or related dementias, at least one of whom shall be a psychiatrist ] and related disorders or other 18 forms of dementia<sup>1</sup>; one <sup>1</sup>[personal care assistant, one homemaker-19 20 home health aide, and one certified nurse aide, each of whom 21 provides] <u>caregiver who provides</u><sup>1</sup> paid services to persons with 22 Alzheimer's disease or related <sup>1</sup>[dementias] disorders or other forms of dementia<sup>1</sup>; one <sup>1</sup>[citizen who is an]<sup>1</sup> unpaid caregiver of 23 a family member who has Alzheimer's disease or a related <sup>1</sup>disorder 24 or other form of  $^1$  dementia;  $^1and^1$  one  $^1$  [citizen] <u>neurologist</u> who 25 <sup>1</sup>[is an unpaid caregiver of a family member who has both] 26 provides specialized services to persons with<sup>1</sup> Alzheimer's disease 27 or a related  ${}^{1}$ <u>disorder or other form of</u>  ${}^{1}$  dementia  ${}^{1}$ <u>[</u>and at least one 28 29 other significant co-occurring disease, disorder, or condition; and 30 one senior citizen 65 years of age or older. Of the public members 31 appointed to the commission, not more than five shall be of the 32 same political party]<sup>1</sup>.

33 c. Each public member of the commission shall serve for a 34 term of four years; however, of the public members first appointed, two shall serve an initial term of one year, three shall serve an 35 initial term of two years, <sup>1</sup>[three] two<sup>1</sup> shall serve an initial term of 36 37 three years, and two shall serve an initial term of four years. Each 38 public member shall serve for the term of their appointment and 39 until a successor is appointed and qualified, except that a public 40 member may be reappointed to the commission upon the expiration of <sup>1</sup>[their] the member's<sup>1</sup> term. 41

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

1 e. Any member of the commission may be removed by the 2 Governor, for cause, after a public hearing. 3 f. The commission shall organize as soon as practicable, but 4 not later than the 30th day  ${}^{1}$ [,]  ${}^{1}$  following the appointment of a majority of its members 1,1 and shall annually elect a chairperson 5 and vice-chairperson from among its members. The chairperson 6 shall appoint a secretary  ${}^{1}[,]^{1}$  who need not be a member of the 7 8 commission. 9 g. Each year, the commission shall meet pursuant to a schedule 10 to be established at its first annual meeting. The commission shall 11 additionally meet at the call of its chairperson or <sup>1</sup>[the Commissioners of Health or Human Services] at the call of the 12 Commissioner of Health or the Commissioner of Human Services<sup>1</sup>. 13 In no case shall the commission meet <sup>1</sup>[less] <u>fewer</u><sup>1</sup> than four times 14 15 per year. h. A majority of the total number of members currently 16 17 appointed to the commission shall constitute a quorum. A vacancy 18 in the membership of the commission shall not impair the ability of 19 the commission to exercise its duties and effectuate its purposes. 20 The commission may conduct business without a quorum, but may only vote on recommendations when a quorum is present. 21 Recommendations shall be approved by a majority of the members 22 23 present. 24 i. The members of the commission shall serve without compensation, but shall be reimbursed for travel and other 25 <sup>1</sup>[miscellaneous] <u>necessary</u><sup>1</sup> expenses incurred in the <sup>1</sup>[necessary]<sup>1</sup> 26 performance of their duties, within the limits of funds made 27 28 available to the commission for its purposes. 29 The commission shall have the power to: j. 30 (1) adopt, amend, or repeal suitable bylaws for the management 31 of its affairs: 32 (2) maintain an office at such place or places as it shall 33 designate; 34 (3) solicit, receive, accept, and expend any grant moneys or 35 other funds that may be made available for its purposes by any government agency or any private for-profit or not-for-profit 36 37 organization or entity; 38 (4) solicit and receive assistance and services from any State, 39 county, or municipal department, board, commission, or agency, as it may require  ${}^{1}$ [,]  ${}^{1}$  and as may be available to it for its purposes; 40 41 (5) enter into any and all agreements or contracts, execute any 42 and all instruments, and do and perform any and all acts or things 43 necessary, convenient, or desirable to further the commission's 44 purposes; and 45 (6) consult with, and solicit and receive testimony from, any 46 association, organization, department, agency, or individual having 47 knowledge of, and experience with: (a) the treatment and care of,

1 or provision of caregiving and personal care services to, persons with Alzheimer's disease and <sup>1</sup>related disorders or<sup>1</sup> other 2 <sup>1</sup>[dementias] forms of dementia<sup>1</sup>; (b) the status or quality of the 3 State's professional workforce in relation to Alzheimer's disease 4 5 and dementia care; (c) the emotional, physical, or financial effects of Alzheimer's disease and <sup>1</sup>related disorders or <sup>1</sup> other <sup>1</sup>[dementias] 6 7 forms of dementia<sup>1</sup> on individuals, families, and the State; or (d) any 8 other issues related to Alzheimer's disease or dementia.

9 k. The Department of Human Services shall provide
10 professional and clerical staff to the commission<sup>1</sup>[,]<sup>1</sup> as may be
11 necessary to effectuate the purposes of this act.

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3. a. The Alzheimer's and Dementia Care Long-Term Planning
Commission <sup>1</sup>[,]<sup>1</sup> established pursuant to this act <sup>1</sup>[,]<sup>1</sup> shall have
the ongoing duty to:

(1) study the incidence, prevalence, and impact of Alzheimer's
disease and related <sup>1</sup>[dementias] <u>disorders or other forms of</u>
<u>dementia</u><sup>1</sup> in the State and in each region of the State and make
projections about the future Statewide and regional incidence,
prevalence, and impact of these conditions;

21 gather, analyze, and disseminate to health care professionals, (2)22 policymakers, and members of the public, as appropriate, data and 23 information about: (a) the needs of persons with Alzheimer's disease and related <sup>1</sup>[dementias] disorders or other forms of 24 dementia<sup>1</sup>, as well as the needs of their family members and 25 26 caregivers; (b) the quality and consistency of care that is provided to persons with Alzheimer's disease and related <sup>1</sup>[dementias] 27 disorders or other forms of dementia<sup>1</sup> in the State <sup>1</sup>, including those 28 29 members of the medically underserved community, the poor 30 community, and the lesbian, gay, bisexual, transgender, <u>questioning</u>, <u>queer</u>, and intersex (LGBTQI) communities<sup>1</sup>; (c) the 31 affordability of Alzheimer's and dementia care in the State and the 32 33 actual and projected Statewide costs and individual costs associated with Alzheimer's disease and related <sup>1</sup> [dementias] <u>disorders or other</u> 34 forms of dementia<sup>1</sup> in New Jersey, including, but not limited to, the 35 costs of health care, mental health care, long-term care, and personal 36 37 care, and ancillary or incidental costs such as those associated with the 38 lost work productivity of, or the treatment of stress-related physical conditions or depression and other mental health conditions in, family 39 caregivers; (d) the <sup>1</sup>[cost-savings] <u>cost savings</u><sup>1</sup> attained by the State 40 through the provision of unpaid caregiving and personal care services 41 42 by family caregivers; (e) the capacity of the State's health care and 43 long-term care facilities to house and provide specialized services to 44 persons with Alzheimer's <sup>1</sup>[or related dementias] disease and related disorders or other forms of dementia<sup>1</sup>; (f) the status of Alzheimer's 45 46 and dementia care in other states, as compared to New Jersey; and (g)

any other issue deemed by the commission to be relevant to effectuate
 the purposes of this act;

3 (3) assess the availability and affordability of existing programs, services, facilities, and agencies in the State that are used to meet 4 the needs of persons with Alzheimer's disease <sup>1</sup>and related 5 disorders<sup>1</sup> or other <sup>1</sup>[dementias] forms of dementia<sup>1</sup> and the needs 6 7 of their families and caregivers; evaluate the capacity of those 8 existing policies, programs, services, facilities, and agencies to 9 adapt to and adequately address the changing needs of dementia 10 patients and their families and caregivers in the face of a 11 continually increasing demand for services; and identify and 12 recommend improvements to existing policies, programs, services, 13 facilities, or agencies or the institution of new policies, programs, 14 services, facilities, or agencies to address unmet and expanding 15 needs in this area;

16 (4) study and outline the appropriate roles of State government, 17 local governments, and health care facilities and professionals in 18 providing or ensuring the provision of appropriate services and other assistance to persons with Alzheimer's disease <sup>1</sup>and related 19 disorders<sup>1</sup> or <sup>1</sup>[related dementias] or other forms of dementia<sup>1</sup>, 20 21 including persons in early stages of disease, and in providing or 22 ensuring the provision of sufficient supportive and assistive 23 services, including training and respite services, to unpaid family 24 caregivers; and identify ways in which State and local governments 25 and health care systems could increase their awareness of, and 26 improve their ability to more effectively address, issues affecting 27 persons with Alzheimer's disease <sup>1</sup>and related disorders<sup>1</sup> or other <sup>1</sup>[dementias] <u>forms of dementia</u><sup>1</sup> and their families; 28

(5) review and analyze the capacity of law enforcement officers
and emergency medical responders in the State to compassionately
and effectively interact with, diffuse conflicts involving, and
provide emergency services to, persons with Alzheimer's disease
and related <sup>1</sup>[dementias] disorders or other forms of dementia<sup>1</sup>;

34 (6) identify and recommend best practices and training (a) health care and mental health care 35 requirements for: 36 professionals, particularly geriatric specialists and primary care 37 practitioners, who are or will be practicing on the front lines of Alzheimer's and dementia care, in order to ensure that such 38 39 professionals are properly trained and are capable of accurately and 40 timely diagnosing Alzheimer's disease and related <sup>1</sup>[dementias] disorders or other forms of dementia,<sup>1</sup> understanding the progression 41 42 of the disease, and recognizing and responding to the evolving 43 needs of patients; (b) personal care professionals who provide 44 services to patients with Alzheimer's disease <sup>1</sup>[or related dementias] and related disorders or other forms of dementia<sup>1</sup>, in 45 46 order to ensure that such professionals are capable of providing 47 compassionate and high quality personal care services and adapting

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to the evolving needs of their patients; and (c) law enforcement officers, emergency medical responders, and other public safety officers, in order to ensure that those officers understand the complexities of dealing with persons with Alzheimer's disease and **1**[other dementias] related disorders or other forms of dementia<sup>1</sup> and are better prepared to compassionately diffuse or resolve conflicts and respond to emergencies involving such persons;

8 (7) evaluate the sufficiency of the State's Alzheimer's and 9 dementia care workforce, identify current and future workforce 10 needs, anticipate future workforce shortages, develop innovative 11 strategies to encourage and increase the recruitment and retention of 12 health care, mental health care, direct support, and personal care 13 professionals who are trained to provide Alzheimer's and dementia 14 care, and take any other action necessary to encourage and facilitate 15 the development and maintenance of a robust and specialized professional Statewide workforce that is capable of delivering high 16 17 quality Alzheimer's and dementia-related care to a rapidly growing 18 population in the State; and

19 (8) study and make recommendations on any other issue related
20 to Alzheimer's disease <sup>1</sup>[or other dementias] and related disorders
21 or other forms of dementia<sup>1</sup>.

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

(1) the commission's annual findings on the issues described insubsection a. of this section;

29 (2) a description as to whether, how, and why the commission's 30 findings have changed over time, including an indication as to the 31 implementation status of the commission's prior recommendations, 32 a description of actions that have been undertaken by any person or 33 public or private entity in the State over the prior reporting period 34 to implement those prior recommendations, and a description of the 35 perceived or documented effects resulting from implementation of 36 those prior recommendations;

37 (3) a copy of, or reference to, the statistical, demographic, 38 testimonial, or other data or information that was used by the 39 commission to: (a) support its current findings under paragraph (1) 40 of this subsection; or (b) inform its analysis of the impact of the 41 commission's prior recommendations under paragraph (2) of this 42 subsection. The data provided pursuant to this paragraph shall be 43 presented in aggregate form and shall not contain the personally 44 identifying information of any patient, caregiver, or other person; 45 and

46 (4) the commission's recommendations for legislative, executive,
47 or other actions that can be undertaken, or strategies that can be
48 implemented, to: (a) improve the quality, consistency, or

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1 affordability of Alzheimer's and dementia care in the State and 2 ensure its accessibility to all who need it; (b) reduce, eliminate, or mitigate the societal and individual impact of, and the Statewide, 3 4 local, and individual costs or financial burdens associated with, 5 Alzheimer's disease and <sup>1</sup>[other dementias] <u>related disorders or</u> other forms of dementia<sup>1</sup>; (c) ensure that the State's professional 6 7 workforce is adequately trained, is capable of providing affordable, 8 high quality Alzheimer's and dementia care throughout the State, 9 and is sufficient in numbers and flexible enough to adapt to a 10 rapidly increasing demand for services in the State; (d) ensure that 11 unpaid caregivers in the State are recognized for their dedicated 12 service and significant contributions to society and are provided 13 with sufficient supportive and respite services, as well as financial 14 assistance where possible and appropriate, as may be necessary for 15 them to capably perform their caregiving tasks while avoiding 16 unnecessary physical, mental, or financial strain; or (e) otherwise 17 address the issues or mitigate the problems identified by the 18 commission in its annual findings. 19

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4. P.L.2011, c.76 (C.26:2M-16 et seq.) is repealed.

22 5. This act shall take effect immediately.