

# ASSEMBLY, No. 4422

## STATE OF NEW JERSEY 219th LEGISLATURE

INTRODUCED JULY 20, 2020

**Sponsored by:**

**Assemblywoman VALERIE VAINIERI HUTTLE**

**District 37 (Bergen)**

**Assemblyman NICHOLAS CHIARAVALLOTI**

**District 31 (Hudson)**

**Assemblyman DANIEL R. BENSON**

**District 14 (Mercer and Middlesex)**

**Co-Sponsored by:**

**Assemblyman Mukherji, Assemblywomen Chaparro, Dunn, McKnight,  
Gove and Assemblyman Danielsen**

**SYNOPSIS**

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

**CURRENT VERSION OF TEXT**

As introduced.



**(Sponsorship Updated As Of: 12/7/2020)**

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).

46 e. In addition to burdening the person who suffers from the  
47 disease, Alzheimer's disease and related dementias place a  
48 tremendous and years-long burden on caregivers, particularly

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

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

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

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

45 i. In 2019, total per-person health care and long-term care  
46 payments from all sources for Medicare beneficiaries with  
47 Alzheimer's or other dementias were over three times as great as  
48 payments for other Medicare beneficiaries in the same age group

1 (\$50,201 per person for those with dementia compared with  
2 \$14,326 per person for those without dementia).

3 j. In New Jersey, it is expected that total Medicaid payments  
4 for persons age 65 and older who are living with Alzheimer's will  
5 amount to nearly \$2.2 billion in 2020 and will increase more than  
6 19 percent to \$2.6 billion by 2025.

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

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

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

33 n. There is currently a shortage of specialized geriatric  
34 professionals in the State and nation to meet the needs of the rapidly  
35 growing aging population and the complex needs of aging  
36 individuals who are living with Alzheimer's disease and related  
37 dementias. The Alzheimer's Association *2020 Facts and Figures*  
38 report estimates that, by 2030, an additional 23,750 geriatricians  
39 will be needed to meet the needs of the aging population  
40 nationwide. In New Jersey, moreover, the shortage of geriatricians  
41 is particularly great. As of 2019, the State had only 205  
42 geriatricians. The *2020 Facts and Figures* report indicates that, by  
43 2050, the State will need at least 398 geriatricians to serve a mere  
44 10 percent of the population aged 65 years or older and will require  
45 a nearly six-fold increase in geriatricians (or a total of 1,193  
46 geriatricians) to serve 30 percent of the population in this age  
47 group.

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

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

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

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

37  
38 2. a. The Alzheimer's and Dementia Care Long-Term  
39 Planning Commission is established in the Department of Human  
40 Services. The purpose of the commission shall be to provide for the  
41 ongoing evaluation of the State's Alzheimer's disease and dementia  
42 care system and identify various innovative means and methods that  
43 can be used to address the significant shortcomings in that care  
44 system and otherwise expand and prepare the system to meet the  
45 increasing and evolving needs of a rapidly aging population.

46 b. The commission shall consist of 31 members, including:

47 (1) the Commissioner of Health, the Commissioner of Human  
48 Services, the New Jersey Long Term Care Ombudsman, the

1 Director of the Division of Aging Services in the Department of  
2 Human Services, the Director of the Office of the Public Guardian  
3 for the Elderly in the Department of Human Services, the Director  
4 of the Office of Minority and Multicultural Health in the  
5 Department of Health, the Director of the Division of Medical  
6 Assistance and Health Services in the Department of Human  
7 Services, the President of Alzheimer's New Jersey, the Executive  
8 Director of the Alzheimer's Association Greater New Jersey  
9 Chapter, the Executive Director of the Alzheimer's Association  
10 Delaware Valley Chapter, the President of the New Jersey Health  
11 Care Quality Institute, the President of the Home Care and Hospice  
12 Association of New Jersey, the President of the New Jersey  
13 Hospital Association, the President of LeadingAge New Jersey, the  
14 Executive Director of Caregivers of New Jersey, the President of  
15 the New Jersey chapter of the AARP, and the Executive Director of  
16 the National Alliance on Mental Illness in New Jersey, or their  
17 designees, who shall serve ex officio;

18 (2) two members of the Senate who are not of the same political  
19 party, one of whom shall be appointed by the President of the  
20 Senate and one of whom shall be appointed by the Senate Minority  
21 Leader;

22 (3) two members of the General Assembly who are not of the  
23 same political party, one of whom shall be appointed by the Speaker  
24 of the General Assembly and one of whom shall be appointed by  
25 the Minority Leader of the General Assembly; and

26 (4) 10 public members to be appointed by the Governor as  
27 follows: two health care professionals who are currently involved  
28 in the provision of direct services to patients with Alzheimer's  
29 disease or other related dementias, one of whom shall be a geriatric  
30 specialist and one of whom shall be a primary care physician; two  
31 mental health care professionals who provide specialized services to  
32 persons with Alzheimer's disease or related dementias, at least one  
33 of whom shall be a psychiatrist; one personal care assistant, one  
34 homemaker-home health aide, and one certified nurse aide, each of  
35 whom provides paid services to persons with Alzheimer's disease  
36 or related dementias; one citizen who is an unpaid caregiver of a  
37 family member who has Alzheimer's disease or a related dementia;  
38 one citizen who is an unpaid caregiver of a family member who has  
39 both Alzheimer's disease or a related dementia and at least one  
40 other significant co-occurring disease, disorder, or condition; and  
41 one senior citizen 65 years of age or older. Of the public members  
42 appointed to the commission, not more than five shall be of the  
43 same political party.

44 c. Each public member of the commission shall serve for a  
45 term of four years; however, of the public members first appointed,  
46 two shall serve an initial term of one year, three shall serve an  
47 initial term of two years, three shall serve an initial term of three  
48 years, and two shall serve an initial term of four years. Each public

1 member shall serve for the term of their appointment and until a  
2 successor is appointed and qualified, except that a public member  
3 may be reappointed to the commission upon the expiration of their  
4 term.

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

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

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

16 g. Each year, the commission shall meet pursuant to a schedule  
17 to be established at its first annual meeting. The commission shall  
18 additionally meet at the call of its chairperson or the Commissioners  
19 of Health or Human Services. In no case shall the commission meet  
20 less than four times per year.

21 h. A majority of the total number of members currently  
22 appointed to the commission shall constitute a quorum. A vacancy  
23 in the membership of the commission shall not impair the ability of  
24 the commission to exercise its duties and effectuate its purposes.  
25 The commission may conduct business without a quorum, but may  
26 only vote on recommendations when a quorum is present.  
27 Recommendations shall be approved by a majority of the members  
28 present.

29 i. The members of the commission shall serve without  
30 compensation, but shall be reimbursed for travel and other  
31 miscellaneous expenses incurred in the necessary performance of  
32 their duties, within the limits of funds made available to the  
33 commission for its purposes.

34 j. The commission shall have the power to:

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

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

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

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

46 (5) enter into any and all agreements or contracts, execute any  
47 and all instruments, and do and perform any and all acts or things

1 necessary, convenient, or desirable to further the commission's  
2 purposes; and

3 (6) consult with, and solicit and receive testimony from, any  
4 association, organization, department, agency, or individual having  
5 knowledge of, and experience with: (a) the treatment and care of,  
6 or provision of caregiving and personal care services to, persons  
7 with Alzheimer's disease and other dementias; (b) the status or  
8 quality of the State's professional workforce in relation to  
9 Alzheimer's disease and dementia care; (c) the emotional, physical,  
10 or financial effects of Alzheimer's disease and other dementias on  
11 individuals, families, and the State; or (d) any other issues related to  
12 Alzheimer's disease or dementia.

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

16

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

20 (1) study the incidence, prevalence, and impact of Alzheimer's  
21 disease and related dementias in the State and in each region of the  
22 State and make projections about the future Statewide and regional  
23 incidence, prevalence, and impact of these conditions;

24 (2) gather, analyze, and disseminate to health care professionals,  
25 policymakers, and members of the public, as appropriate, data and  
26 information about: (a) the needs of persons with Alzheimer's  
27 disease and related dementias, as well as the needs of their family  
28 members and caregivers; (b) the quality and consistency of care that  
29 is provided to persons with Alzheimer's disease and related  
30 dementias in the State; (c) the affordability of Alzheimer's and  
31 dementia care in the State and the actual and projected Statewide  
32 costs and individual costs associated with Alzheimer's disease and  
33 related dementias in New Jersey, including, but not limited to, the  
34 costs of health care, mental health care, long-term care, and  
35 personal care, and ancillary or incidental costs such as those  
36 associated with the lost work productivity of, or the treatment of  
37 stress-related physical conditions or depression and other mental  
38 health conditions in, family caregivers; (d) the cost-savings attained  
39 by the State through the provision of unpaid caregiving and  
40 personal care services by family caregivers; (e) the capacity of the  
41 State's health care and long-term care facilities to house and  
42 provide specialized services to persons with Alzheimer's or related  
43 dementias; (f) the status of Alzheimer's and dementia care in other  
44 states, as compared to New Jersey; and (g) any other issue deemed  
45 by the commission to be relevant to effectuate the purposes of this  
46 act;

47 (3) assess the availability and affordability of existing programs,  
48 services, facilities, and agencies in the State that are used to meet



1 the needs of persons with Alzheimer's disease or other dementias  
2 and the needs of their families and caregivers; evaluate the capacity  
3 of those existing policies, programs, services, facilities, and  
4 agencies to adapt to and adequately address the changing needs of  
5 dementia patients and their families and caregivers in the face of a  
6 continually increasing demand for services; and identify and  
7 recommend improvements to existing policies, programs, services,  
8 facilities, or agencies or the institution of new policies, programs,  
9 services, facilities, or agencies to address unmet and expanding  
10 needs in this area;

11 (4) study and outline the appropriate roles of State government,  
12 local governments, and health care facilities and professionals in  
13 providing or ensuring the provision of appropriate services and  
14 other assistance to persons with Alzheimer's disease or related  
15 dementias, including persons in early stages of disease, and in  
16 providing or ensuring the provision of sufficient supportive and  
17 assistive services, including training and respite services, to unpaid  
18 family caregivers; and identify ways in which State and local  
19 governments and health care systems could increase their awareness  
20 of, and improve their ability to more effectively address, issues  
21 affecting persons with Alzheimer's disease or other dementias and  
22 their families;

23 (5) review and analyze the capacity of law enforcement officers  
24 and emergency medical responders in the State to compassionately  
25 and effectively interact with, diffuse conflicts involving, and  
26 provide emergency services to, persons with Alzheimer's disease  
27 and related dementias;

28 (6) identify and recommend best practices and training  
29 requirements for: (a) health care and mental health care  
30 professionals, particularly geriatric specialists and primary care  
31 practitioners, who are or will be practicing on the front lines of  
32 Alzheimer's and dementia care, in order to ensure that such  
33 professionals are properly trained and are capable of accurately and  
34 timely diagnosing Alzheimer's disease and related dementias,  
35 understanding the progression of the disease, and recognizing and  
36 responding to the evolving needs of patients; (b) personal care  
37 professionals who provide services to patients with Alzheimer's  
38 disease or related dementias, in order to ensure that such  
39 professionals are capable of providing compassionate and high  
40 quality personal care services and adapting to the evolving needs of  
41 their patients; and (c) law enforcement officers, emergency medical  
42 responders, and other public safety officers, in order to ensure that  
43 those officers understand the complexities of dealing with persons  
44 with Alzheimer's disease and other dementias and are better  
45 prepared to compassionately diffuse or resolve conflicts and  
46 respond to emergencies involving such persons;

47 (7) evaluate the sufficiency of the State's Alzheimer's and  
48 dementia care workforce, identify current and future workforce

1 needs, anticipate future workforce shortages, develop innovative  
2 strategies to encourage and increase the recruitment and retention of  
3 health care, mental health care, direct support, and personal care  
4 professionals who are trained to provide Alzheimer's and dementia  
5 care, and take any other action necessary to encourage and facilitate  
6 the development and maintenance of a robust and specialized  
7 professional Statewide workforce that is capable of delivering high  
8 quality Alzheimer's and dementia-related care to a rapidly growing  
9 population in the State; and

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

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

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

19 (2) a description as to whether, how, and why the commission's  
20 findings have changed over time, including an indication as to the  
21 implementation status of the commission's prior recommendations,  
22 a description of actions that have been undertaken by any person or  
23 public or private entity in the State over the prior reporting period  
24 to implement those prior recommendations, and a description of the  
25 perceived or documented effects resulting from implementation of  
26 those prior recommendations;

27 (3) a copy of, or reference to, the statistical, demographic,  
28 testimonial, or other data or information that was used by the  
29 commission to: (a) support its current findings under paragraph (1)  
30 of this subsection; or (b) inform its analysis of the impact of the  
31 commission's prior recommendations under paragraph (2) of this  
32 subsection. The data provided pursuant to this paragraph shall be  
33 presented in aggregate form and shall not contain the personally  
34 identifying information of any patient, caregiver, or other person;  
35 and

36 (4) the commission's recommendations for legislative,  
37 executive, or other actions that can be undertaken, or strategies that  
38 can be implemented, to: (a) improve the quality, consistency, or  
39 affordability of Alzheimer's and dementia care in the State and  
40 ensure its accessibility to all who need it; (b) reduce, eliminate, or  
41 mitigate the societal and individual impact of, and the Statewide,  
42 local, and individual costs or financial burdens associated with,  
43 Alzheimer's disease and other dementias; (c) ensure that the State's  
44 professional workforce is adequately trained, is capable of  
45 providing affordable, high quality Alzheimer's and dementia care  
46 throughout the State, and is sufficient in numbers and flexible  
47 enough to adapt to a rapidly increasing demand for services in the  
48 State; (d) ensure that unpaid caregivers in the State are recognized

1 for their dedicated service and significant contributions to society  
2 and are provided with sufficient supportive and respite services, as  
3 well as financial assistance where possible and appropriate, as may  
4 be necessary for them to capably perform their caregiving tasks  
5 while avoiding unnecessary physical, mental, or financial strain; or  
6 (e) otherwise address the issues or mitigate the problems identified  
7 by the commission in its annual findings.

8  
9 4. P.L.2011, c.76 (C.26:2M-16 et seq.) is repealed.

10  
11 5. This act shall take effect immediately.

12  
13  
14 STATEMENT

15  
16 This bill would permanently establish an “Alzheimer’s and  
17 Dementia Care Long-Term Planning Commission” in the  
18 Department of Human Services (DHS) to provide for the ongoing  
19 evaluation of the State’s Alzheimer’s disease and dementia care  
20 system and identify means and methods that can be used to address  
21 significant shortcomings in the system or otherwise expand and  
22 prepare the system to meet the increasing and evolving needs of a  
23 rapidly aging population.

24 Although the State has previously attempted to identify and  
25 address issues associated with Alzheimer’s disease and related  
26 dementias through the enactment of P.L.1983, c.352 (C.26:2M-1 et  
27 seq.) and P.L.2011, c.76 (C.26:2M-16 et seq.) and the establishment  
28 of two different study commissions thereunder, each of those study  
29 commissions was temporary in nature and dissolved after the  
30 submission of a single report. As evidenced by the bill’s findings  
31 and declarations, however, Alzheimer’s disease and other dementias  
32 continue to have severe ongoing and worsening impacts on the State  
33 and its residents, there are projections for a rapid increase in the  
34 number of persons presenting with these conditions into the future,  
35 and New Jersey lacks the robust professional workforce necessary  
36 to address the concerns of this growing population of patients and  
37 their families. As a result, there is a significant need for the State to  
38 establish a permanent commission to engage in a concerted,  
39 proactive, and ongoing effort to study and develop innovative  
40 solutions to address and mitigate the effects of Alzheimer’s disease  
41 and related dementias on citizens of this State, both now and into  
42 the future.

43 The Alzheimer’s and Dementia Care Long-Term Planning  
44 Commission would consist of 31 members, including 17 ex officio  
45 members from a wide array of State agencies and non-profit  
46 organizations that are on the front lines of Alzheimer’s and  
47 dementia care; four legislative members, with one each being  
48 appointed by the Senate President, the Senate Minority Leader, the

1 Speaker of the General Assembly, and the Minority Leader of the  
2 General Assembly; and 10 public members who are variously  
3 involved with or impacted by Alzheimer's disease or dementia care,  
4 as specified by the bill, to be appointed by the Governor. No more  
5 than five of the public members may be of the same political party.  
6 All initial appointments to the commission are to be made within 60  
7 days after the bill's effective date, and the commission is to  
8 organize as soon as practicable, but not later than the 30th day,  
9 following the appointment of a majority of its members.

10 The commission will be required to meet each year, pursuant to a  
11 schedule to be established at its first annual meeting. The  
12 commission will additionally be required to meet at the call of its  
13 chairperson or the Commissioners of Health or Human Services. In  
14 no case may the commission meet less than four times per year.

15 The commission will have the duty, on an ongoing basis, to:

16 1) study the incidence, prevalence, and impact of Alzheimer's  
17 disease and related dementias in the State and in each region of the  
18 State and make projections about the future Statewide and regional  
19 incidence, prevalence, and impact of these conditions;

20 2) gather, analyze, and disseminate to health care professionals,  
21 policymakers, and members of the public, as appropriate, various  
22 types of data and information, as specified in the bill, related to  
23 Alzheimer's and dementia care in the State and the needs of persons  
24 with Alzheimer's disease and related dementias, as well as the  
25 needs of their family members and caregivers;

26 3) assess the availability and affordability of existing programs,  
27 services, facilities, and agencies in the State that are used to meet  
28 the needs of persons with Alzheimer's disease or other dementias  
29 and the needs of their families and caregivers; evaluate the capacity  
30 of those existing policies, programs, services, facilities, and  
31 agencies to adapt to and adequately address the changing needs of  
32 dementia patients and their families and caregivers in the face of a  
33 continually increasing demand for services; and identify and  
34 recommend improvements to existing policies, programs, services,  
35 facilities, or agencies or the institution of new policies, programs,  
36 services, facilities, or agencies to address unmet and expanding  
37 needs in this area;

38 4) study and outline the appropriate roles of State government,  
39 local governments, and health care facilities and professionals in  
40 providing or ensuring the provision of appropriate services and  
41 other assistance to persons with Alzheimer's disease or related  
42 dementias, including persons in early stages of disease, and in  
43 providing or ensuring the provision of sufficient supportive and  
44 assistive services, including training and respite services, to unpaid  
45 family caregivers; and identify ways in which State and local  
46 governments and health care systems could increase their awareness  
47 of, and improve their ability to more effectively address, issues

1 affecting persons with Alzheimer's disease or other dementias and  
2 their families;

3 5) review and analyze the capacity of law enforcement officers  
4 and emergency medical responders in the State to compassionately  
5 and effectively interact with, diffuse conflicts involving, and  
6 provide emergency services to, persons with Alzheimer's disease  
7 and related dementias;

8 6) identify and recommend dementia-related best practices and  
9 training requirements for: a) health care and mental health care  
10 professionals, particularly geriatric specialists and primary care  
11 practitioners, who are or will be practicing on the front lines of  
12 Alzheimer's and dementia care; b) personal care professionals who  
13 provide services to patients with Alzheimer's disease or related  
14 dementias; and c) law enforcement officers, emergency medical  
15 responders, and other public safety officers;

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

27 8) study and make recommendations on any other issue related  
28 to Alzheimer's disease or other dementias.

29 One year after the commission's organizational meeting, and  
30 annually thereafter, the commission will be required to prepare and  
31 submit a written report to the Governor and the Legislature. The  
32 written report is to contain, at a minimum:

33 1) the commission's annual findings on the issues within the  
34 commission's purview;

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

43 3) a copy of, or reference to, the de-personalized statistical,  
44 demographic, testimonial, or other data or information that was  
45 used by the commission either to support its current findings or  
46 inform its analysis of the impact of the commission's prior  
47 recommendations; and

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

21       In performing its duties under the bill, the commission would  
22 have the power to:

23       1) adopt, amend, or repeal suitable bylaws for the management  
24 of its affairs;

25       2) maintain an office at such place or places as it may  
26 designate;

27       3) solicit, receive, accept, and expend any grant moneys or  
28 other funds that may be made available for its purposes by any  
29 government agency or any private for-profit or not-for-profit  
30 organization or entity;

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

34       5) enter into any and all agreements or contracts, execute any  
35 and all instruments, and do and perform any and all acts or things  
36 necessary, convenient, or desirable to further the commission's  
37 purposes; and

38       6) consult with, and solicit and receive testimony from, any  
39 association, organization, department, agency, or individual having  
40 knowledge of, and experience with issues related to Alzheimer's  
41 disease or other dementias.

42       The Department of Human Services would be required to  
43 provide professional and clerical staff to the commission.