

[First Reprint]

**SENATE, No. 1033**

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**STATE OF NEW JERSEY**  
**220th LEGISLATURE**

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INTRODUCED JANUARY 31, 2022

**Sponsored by:**

**Senator JOSEPH F. VITALE**

**District 19 (Middlesex)**

**Co-Sponsored by:**

**Senators Diegnan, Johnson, Madden, Singleton, Stanfield, Turner and Polistina**

**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 May 12, 2022, with amendments.



**(Sponsorship Updated As Of: 5/26/2022)**

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 and  
 11 related disorders that develop over a period of years, are of an  
 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  
 19 of daily life such as walking, dressing, feeding, and bathing.

20 b. According to a <sup>1</sup>~~2020~~ <sup>2022</sup> *Facts and Figures* report  
 21 released by the Alzheimer's Association, nearly six <sup>1</sup>~~and a half~~<sup>1</sup>  
 22 million Americans age 65 or older, or one out of every <sup>1</sup>~~10~~ <sup>nine</sup><sup>1</sup>  
 23 Americans in this age group, are currently living with Alzheimer's  
 24 disease. Barring the development of medical breakthroughs to  
 25 prevent, slow, or cure the disease, this number is expected to rise <sup>1</sup>~~by~~  
 26 ~~a factor of 22 percent~~<sup>1</sup> to 7.1 million by 2025, and to increase <sup>1</sup>~~by~~  
 27 ~~a factor of 33 percent~~<sup>1</sup> to 13.8 million by <sup>1</sup>~~2050~~ <sup>2060</sup><sup>1</sup>. In New  
 28 Jersey, the total number of seniors living with Alzheimer's, which was  
 29 190,000 in the year <sup>1</sup>~~2020~~ <sup>2022</sup><sup>1</sup> is expected to increase by more  
 30 than 10 percent, to 210,000, by the year 2025.

31 c. Although the complexities of death reporting systems make it  
 32 difficult to accurately determine the total number of deaths that have  
 33 been directly or indirectly caused by Alzheimer's disease, the  
 34 Alzheimer's Association <sup>1</sup>~~2020~~ <sup>2022</sup><sup>1</sup> *Facts and Figures* report  
 35 estimated the <sup>1</sup>~~2018~~ <sup>2019</sup><sup>1</sup> mortality rate for this disease to be  
 36 <sup>1</sup>~~37.3~~ <sup>37.0</sup><sup>1</sup> deaths for every 100,000 people nationwide and  
 37 <sup>1</sup>~~30.4~~ <sup>29.6</sup><sup>1</sup> deaths for every 100,000 people Statewide in New  
 38 Jersey.

39 d. Alzheimer's disease progresses in a gradual and insidious  
 40 manner. <sup>1</sup>~~While~~ <sup>Although</sup><sup>1</sup> most persons with dementia live <sup>1</sup>~~four~~  
 41 ~~to~~ <sup>eight</sup> <sup>to 10</sup><sup>1</sup> years after receiving their diagnosis, some can live  
 42 as long as 20 years as they continue to lose their ability to function.  
 43 As of 2016, Alzheimer's disease was ranked as the sixth most  
 44 burdensome disease in the nation in terms of total disability-adjusted

**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:

<sup>1</sup>Senate SHH committee amendments adopted May 12, 2022.

1 life years and the fourth most burdensome disease in terms of the total  
2 number of years of life that are lived with a disability.

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

28 f. In <sup>1</sup>【2019】 2021<sup>1</sup>, more than <sup>1</sup>【16】 11<sup>1</sup> million caregivers  
29 provided an estimated <sup>1</sup>【18.6】 16<sup>1</sup> billion hours in unpaid assistance  
30 across the nation to persons with Alzheimer's disease and related  
31 disorders or other forms of dementia – a contribution to the nation that  
32 is valued at <sup>1</sup>【\$244】 \$271.6<sup>1</sup> billion, which is equal to approximately  
33 <sup>1</sup>【11】 14<sup>1</sup> times the total revenue of McDonald's in <sup>1</sup>【2018】 2020<sup>1</sup>.  
34 This included <sup>1</sup>【448】 361<sup>1</sup> caregivers who provided <sup>1</sup>【510】 686<sup>1</sup>  
35 million hours equal to <sup>1</sup>【\$6.6】 more than \$13<sup>1</sup> billion worth of unpaid  
36 care in New Jersey alone.

37 g. Although personal care professionals, certified nurse aides,  
38 homemaker-home health aides, and other direct care professionals may  
39 be capable of providing paid caregiving services to persons with  
40 Alzheimer's disease and related disorders or other forms of dementia,  
41 because of the low pay for caregiving services and the tireless,  
42 difficult, and thankless nature of the work, there is currently a  
43 significant shortage of these professionals in the State, and turnover  
44 rates are high.

45 h. In addition to causing significant physical and mental burdens  
46 both to individuals who have the disease and to their caregivers,  
47 dementia, including Alzheimer's <sup>1</sup>disease and related disorders<sup>1</sup>, is

1 one of the costliest conditions to society. In <sup>1</sup>~~2020~~ 2022<sup>1</sup>, the total  
2 nationwide cost of caring for persons with Alzheimer's disease and  
3 related disorders or other forms of dementia is projected to reach  
4 <sup>1</sup>~~305~~ 321<sup>1</sup> billion, not including <sup>1</sup>~~244~~ 271.6<sup>1</sup> billion in  
5 unpaid caregiver costs. Although Medicaid and Medicare are expected  
6 to cover \$206 billion or <sup>1</sup>~~67~~ 64<sup>1</sup> percent of the total costs of  
7 dementia-related care, out-of-pocket spending is expected to amount to  
8 <sup>1</sup>~~66~~ 81<sup>1</sup> billion in <sup>1</sup>~~2020~~ 2022<sup>1</sup> alone, which is equal to <sup>1</sup>~~22~~  
9 25<sup>1</sup> percent of total payments under the programs.

10 i. In <sup>1</sup>~~2019~~ 2021<sup>1</sup>, total per-person health care and long-term  
11 care payments from all sources for Medicare beneficiaries with  
12 Alzheimer's disease and related disorders or other forms of dementia  
13 were <sup>1</sup>~~50,201~~ 41,757<sup>1</sup> per person for those with dementia and  
14 <sup>1</sup>~~14,326~~ 14,026<sup>1</sup> per person for those without dementia, which is  
15 over three times as great as payments for other Medicare beneficiaries  
16 in the same age group.

17 j. In New Jersey, it is expected that total Medicaid payments for  
18 persons age 65 and older who are living with Alzheimer's disease and  
19 related disorders or other forms of dementia<sup>1</sup> will amount to nearly  
20 \$2.2 billion in 2020 and will increase more than 19 percent to \$2.6  
21 billion by 2025.

22 k. The total lifetime cost of care for someone with Alzheimer's  
23 disease and related disorders or other forms of dementia was estimated  
24 to be <sup>1</sup>~~357,297 in 2019~~ 377,621 in 2021 dollars<sup>1</sup>. According to  
25 the Alzheimer's Association <sup>1</sup>~~2020~~ 2022<sup>1</sup> *Facts and Figures* report,  
26 70 percent of this lifetime cost of care is borne by family caregivers in  
27 the form of unpaid caregiving and payments for out-of-pocket  
28 expenses. These lifetime cost estimates, moreover, likely  
29 underestimate the financial impacts that a person's dementia has on the  
30 health and workplace productivity levels of the person's family  
31 caregiver.

32 l. Persons with dementia <sup>1</sup>, including Alzheimer's disease or a  
33 related disorder,<sup>1</sup> are also more likely than others to have co-occurring  
34 health care conditions. Of persons with Alzheimer's disease and  
35 related disorders or other forms of dementia, <sup>1</sup>~~38~~ 46<sup>1</sup> percent also  
36 have coronary artery disease, 37 percent have diabetes, <sup>1</sup>~~29~~ 46<sup>1</sup>  
37 percent have chronic kidney disease, <sup>1</sup>~~28~~ 34<sup>1</sup> percent have  
38 congestive heart failure, <sup>1</sup>~~25~~ 20<sup>1</sup> percent have chronic obstructive  
39 pulmonary disease, <sup>1</sup>~~22~~ 13<sup>1</sup> percent have stroke-related care, and  
40 <sup>1</sup>~~13~~ 10<sup>1</sup> percent have cancer. Medicare beneficiaries with  
41 Alzheimer's disease and related disorders or other forms of dementia  
42 have higher rates of hospitalization than other patients for all of these  
43 co-occurring conditions and higher average per-person payments in all  
44 categories except in the case of hospital care payments for individuals  
45 with congestive heart failure.

1 m. In general, patients with Alzheimer’s disease and related  
2 disorders or other forms of dementia have a 30 percent greater risk  
3 than other patients of experiencing a preventable hospitalization event,  
4 and patients with both dementia and depression have a 70 percent  
5 greater risk of preventable hospitalization than persons without a  
6 neuropsychiatric disorder.

7 n. There is currently a shortage of specialized geriatric  
8 professionals in the State and nation to meet the needs of the rapidly  
9 growing population of individuals <sup>1</sup>aged age<sup>1</sup> 65 years or older and  
10 the complex needs of aging individuals who are living with  
11 Alzheimer’s disease and related disorders or other forms of dementia.  
12 The Alzheimer’s Association <sup>1</sup>2020 <sup>1</sup>2022<sup>1</sup> *Facts and Figures* report  
13 estimates that, by <sup>1</sup>2030 <sup>1</sup>2050<sup>1</sup> , an additional <sup>1</sup>23,750 <sup>1</sup>41,082<sup>1</sup>  
14 geriatricians will be needed to <sup>1</sup>meet the needs of the aging  
15 population <sup>1</sup>serve 30 percent of people age 65 and older<sup>1</sup> nationwide <sup>1</sup>,  
16 representing a nine-fold increase<sup>1</sup> . In New Jersey, moreover, the  
17 shortage of geriatricians is particularly great. As of <sup>1</sup>2019 <sup>1</sup>2021<sup>1</sup> ,  
18 the State had only <sup>1</sup>205 <sup>1</sup>206<sup>1</sup> geriatricians. The <sup>1</sup>2020 <sup>1</sup>2022<sup>1</sup>  
19 *Facts and Figures* report indicates that, by 2050, the State will need at  
20 least 398 geriatricians to serve a mere 10 percent of the population  
21 <sup>1</sup>aged age<sup>1</sup> 65 years or older and will require a total of 1,193  
22 geriatricians, representing a nearly six-fold increase, to serve 30  
23 percent of the population in this age group.

24 o. With a significant shortage of geriatric specialists to meet  
25 current and future dementia care needs, primary care physicians  
26 (PCPs) will play an increasingly important role in caring for dementia  
27 patients along the continuum of the disease and should, therefore, be  
28 properly trained in identifying the warning signs of Alzheimer’s  
29 disease and related disorders or other forms of dementia, providing  
30 timely and competent <sup>1</sup>dementia<sup>1</sup> diagnoses <sup>1</sup>of dementia, including  
31 Alzheimer’s and related conditions<sup>1</sup> , and meeting the ongoing care  
32 and support needs of patients who are living with <sup>1</sup>Alzheimer’s disease  
33 or a related condition or other form of<sup>1</sup> dementia.

34 p. Although <sup>1</sup>82 <sup>1</sup>75<sup>1</sup> percent of the 1,000 PCPs surveyed for  
35 the <sup>1</sup>2020 <sup>1</sup>2022<sup>1</sup> *Facts and Figures* report indicated that they are  
36 already working on the front lines of <sup>1</sup>caring for patients with<sup>1</sup>  
37 Alzheimer’s <sup>1</sup>care <sup>1</sup>disease and related disorders or other forms of  
38 dementia<sup>1</sup> , half reported that <sup>1</sup>the medical profession is <sup>1</sup>they do<sup>1</sup>  
39 not <sup>1</sup>feel<sup>1</sup> adequately prepared to <sup>1</sup>meet increased demand in this  
40 area <sup>1</sup>care for patients with Alzheimer’s disease and related disorders  
41 or other forms of dementia, and more than half reported that there are  
42 not enough specialists in their area to meet patient demand<sup>1</sup> . These  
43 PCPs also reported a lack of access to sufficient dementia-related  
44 training in medical schools and residency programs, and more than  
45 half indicated that they had not pursued additional training in dementia

1 care following graduation or residency, due to challenges associated  
2 with obtaining such supplemental training.

3 q. Although the State has previously attempted to identify and  
4 address issues associated with Alzheimer's disease and related  
5 disorders or other forms of dementia through the enactment of  
6 P.L.1983, c.352 (C.26:2M-1 et seq.) and P.L.2011, c.76 (C.26:2M-16  
7 et seq.) and the establishment of two different study commissions  
8 thereunder, each of those study commissions was temporary in nature  
9 and dissolved after the submission of a single report.

10 r. In light of the severe ongoing and worsening impacts and  
11 burdens of Alzheimer's disease and related disorders or other forms of  
12 dementia, the projections for rapid increases in the number of persons  
13 presenting with these conditions into the future, and New Jersey's  
14 current lack of a robust professional workforce necessary to address  
15 the concerns of this growing population of patients and their families,  
16 it is both reasonable and necessary for the State to establish a  
17 permanent commission to engage in a concerted, proactive, and  
18 ongoing effort to study and develop innovative solutions to address  
19 and mitigate the effects of this disease on 'the' citizens of this State,  
20 both now and into the future.

21

22 2. a. The Alzheimer's and Dementia Care Long-Term Planning  
23 Commission is established in the Department of Human Services. The  
24 purpose of the commission shall be to provide for the ongoing  
25 evaluation of the State's 'system of care for' Alzheimer's disease and  
26 'related disorders and other forms of' dementia '[care system]' and  
27 identify various innovative means and methods that can be used to  
28 address the '[significant]' shortcomings in that care system and  
29 otherwise expand and prepare the system to meet the increasing and  
30 evolving needs of a rapidly aging population.

31 b. The commission shall consist of 12 members, including:

32 (1) '[Three non-voting ex officio members or their designees as  
33 follows:]' the Commissioner of Health, the Commissioner of Human  
34 Services, and the New Jersey '[Long Term] Long-Term' Care  
35 Ombudsman ' , or their designees, who shall serve as ex officio, non-  
36 voting members' ;

37 (2) two public members to be appointed by the President of the  
38 Senate '[as follows:] , including' one 'member' who '[shall  
39 represent] represents' an organization that advocates for members of  
40 the Alzheimer's 'disease and related disorders or other forms of  
41 dementia' community and one 'member' who '[shall represent]  
42 represents' a for-profit healthcare facility that offers memory care  
43 services;

44 (3) two public members to be appointed by the Speaker of the  
45 General Assembly '[as follows:]' ' , including' one 'member' who  
46 '[shall represent] represents' an organization that advocates for

1 members of the Alzheimer's disease and related disorders or other  
2 forms of dementia<sup>1</sup> community and one member<sup>1</sup> who **1** **shall**  
3 **represent** represents<sup>1</sup> a non-profit healthcare facility that offers  
4 memory care services; and

5 (4) five public members to be appointed by the Governor **1** **as**  
6 **follows** **including**<sup>1</sup> : one geriatrician who is currently involved in the  
7 provision of direct services to patients with Alzheimer's disease and  
8 related disorders or other forms of dementia; one psychiatrist who  
9 provides specialized services to **1** **persons** patients<sup>1</sup> with Alzheimer's  
10 disease and related disorders or other forms of dementia; one caregiver  
11 who provides paid services to persons with Alzheimer's disease or  
12 related disorders or other forms of dementia; one unpaid caregiver of a  
13 family member who has Alzheimer's disease or a related disorder or  
14 other form of dementia; and one neurologist who provides specialized  
15 services to **1** **persons** patients<sup>1</sup> with Alzheimer's disease or a related  
16 disorder or other form of dementia.

17 c. Each public member of the commission shall serve for a term  
18 of four years **1** **;** **however** **1** **,** except that<sup>1</sup> , of the public members first  
19 appointed, two shall serve an initial term of one year, three shall serve  
20 an initial term of two years, two shall serve an initial term of three  
21 years, and two shall serve an initial term of four years. Each public  
22 member shall serve for the term of **1** **their** the member's<sup>1</sup>  
23 appointment and until a successor is appointed and qualified **1** **,** except  
24 that a public member may be reappointed **1** **.** Public members shall be  
25 eligible for reappointment<sup>1</sup> to the commission **1** **upon the expiration of**  
26 **the member's term** **1** **.**

27 d. All initial appointments to the commission shall be made  
28 within 60 days after the effective date of this act. Vacancies in the  
29 membership of the commission shall be filled in the same manner **1** as  
30 is<sup>1</sup> provided for the original appointments.

31 e. **1** **Any member of the commission may be removed by the**  
32 **Governor, for cause, after a public hearing.**

33 **f.**<sup>1</sup> The commission shall organize as soon as practicable, but not  
34 later than the 30th day following the appointment of a majority of its  
35 members, and shall annually elect a chairperson and vice-chairperson  
36 from among its members. The chairperson shall appoint a secretary  
37 who need not be a member of the commission.

38 **g.**<sup>1</sup> **f.**<sup>1</sup> Each year, the commission shall meet pursuant to a  
39 schedule to be established at its first annual meeting. The commission  
40 shall additionally meet at the call of its chairperson or at the call of the  
41 Commissioner of Health or the Commissioner of Human Services. In  
42 no case shall the commission meet fewer than four times per year.

43 **h.**<sup>1</sup> **g.**<sup>1</sup> A majority of the total number of members currently  
44 appointed to the commission shall constitute a quorum. A vacancy in  
45 the membership of the commission shall not impair the ability of the  
46 commission to exercise its duties and effectuate its purposes. The

1 commission may conduct business without a quorum, but may only  
2 vote on recommendations when a quorum is present.  
3 Recommendations shall be approved by a majority of the members  
4 present.

5 <sup>1</sup>**[i.] h.**<sup>1</sup> The members of the commission shall serve without  
6 compensation, but shall be reimbursed for travel and other necessary  
7 expenses incurred in the performance of their duties, within the limits  
8 of funds made available to the commission for its purposes.

9 <sup>1</sup>**[j.] i.**<sup>1</sup> The commission shall have the power to:

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

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

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

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

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

23 (6) consult with, and solicit and receive testimony from, any  
24 association, organization, department, agency, or individual having  
25 knowledge of, and experience with: (a) the treatment and care of, or  
26 provision of caregiving and personal care services to, persons with  
27 Alzheimer's disease and related disorders or other forms of dementia;  
28 (b) the status or quality of the State's professional workforce in  
29 relation to Alzheimer's disease and <sup>1</sup>related disorders and other forms  
30 of<sup>1</sup> dementia care; (c) the emotional, physical, or financial effects of  
31 Alzheimer's disease and related disorders or other forms of dementia  
32 on individuals, families, and the State; or (d) any other issues related to  
33 Alzheimer's disease <sup>1</sup>and related disorders<sup>1</sup> or <sup>1</sup>other forms of<sup>1</sup>  
34 dementia.

35 <sup>1</sup>**[k.] j.**<sup>1</sup> The Department of Human Services shall provide  
36 professional and clerical staff to the commission as may be necessary  
37 to effectuate the purposes of this act.

38  
39 3. a. The Alzheimer's and Dementia Care Long-Term Planning  
40 Commission established pursuant to this act shall have the ongoing  
41 duty to:

42 (1) study the incidence, prevalence, and impact of Alzheimer's  
43 disease and related disorders or other forms of dementia in the State  
44 and in each region of the State and make projections about the future  
45 Statewide and regional incidence, prevalence, and impact of these  
46 conditions;



1 (2) gather, analyze, and disseminate to health care professionals,  
2 policymakers, and members of the public, as appropriate, data and  
3 information about: (a) the needs of persons with Alzheimer's disease  
4 and related disorders or other forms of dementia, as well as the needs  
5 of their family members and caregivers; (b) the quality and  
6 consistency of care that is provided to persons with Alzheimer's  
7 disease and related disorders or other forms of dementia in the State,  
8 including those members of the medically underserved community, the  
9 **'[poor] low income'** community, and the lesbian, gay, bisexual,  
10 transgender, questioning, queer, and intersex (LGBTQI) communities;  
11 (c) the affordability of **'care for'** Alzheimer's **'disease'** and **'related**  
12 **disorders or other forms of'** dementia **'[care]'** in the State and the  
13 actual and projected Statewide costs and individual costs associated  
14 with Alzheimer's disease and related disorders or other forms of  
15 dementia in New Jersey, including, but not limited to, the costs of  
16 health care, mental health care, long-term care, and personal care, and  
17 ancillary or incidental costs such as those associated with the lost work  
18 productivity of, or the treatment of stress-related physical conditions or  
19 depression and other mental health conditions in, family caregivers;  
20 (d) the cost savings attained by the State through the provision of  
21 unpaid caregiving and personal care services by family caregivers; (e)  
22 the capacity of the State's health care and long-term care facilities to  
23 house and provide specialized services to persons with Alzheimer's  
24 disease and related disorders or other forms of dementia; (f) the status  
25 of Alzheimer's **'disease'** and **'related disorders or other forms of'**  
26 dementia care in other states, as compared to New Jersey; and (g) any  
27 other issue deemed by the commission to be relevant to effectuate the  
28 purposes of this act;

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

41 (4) study and outline the appropriate roles of State government,  
42 local governments, and health care facilities and professionals in  
43 providing or ensuring the provision of appropriate services and other  
44 assistance to persons with Alzheimer's disease and related disorders or  
45 **'[or]'** other forms of dementia, including persons in **'the'** early stages  
46 of disease, and in providing or ensuring the provision of sufficient  
47 supportive and assistive services, including training and respite

1 services, to unpaid family caregivers; and identify ways in which State  
2 and local governments and health care systems could increase their  
3 awareness of, and improve their ability to more effectively address,  
4 issues affecting persons with Alzheimer's disease and related disorders  
5 or other forms of dementia and their families;

6 (5) review and analyze the capacity of law enforcement officers  
7 and emergency medical responders in the State to compassionately and  
8 effectively interact with, diffuse conflicts involving, and provide  
9 emergency services to, persons with Alzheimer's disease and related  
10 disorders or other forms of dementia;

11 (6) identify and recommend best practices and training  
12 requirements for: (a) health care and mental health care professionals,  
13 particularly geriatric specialists and primary care practitioners, who  
14 are or will be practicing on the front lines of 'caring for patients with'  
15 Alzheimer's 'disease' and 'related disorders or other forms of'  
16 dementia **'[care]'**, in order to ensure that such professionals are  
17 properly trained and are capable of accurately and timely diagnosing  
18 Alzheimer's disease and related disorders or other forms of dementia,  
19 understanding the progression of the disease, and recognizing and  
20 responding to the evolving needs of patients; (b) personal care  
21 professionals who provide services to patients with Alzheimer's  
22 disease and related disorders or other forms of dementia, in order to  
23 ensure that such professionals are capable of providing compassionate  
24 and high quality personal care services and adapting to the evolving  
25 needs of their patients; and (c) law enforcement officers, emergency  
26 medical responders, and other public safety officers, in order to ensure  
27 that those officers understand the complexities of dealing with persons  
28 with Alzheimer's disease and related disorders or other forms of  
29 dementia and are better prepared to compassionately diffuse or resolve  
30 conflicts and respond to emergencies involving such persons;

31 (7) evaluate the sufficiency of the State's Alzheimer's 'disease'  
32 and 'related disorders or other forms of' dementia care workforce,  
33 identify current and future workforce needs, anticipate future  
34 workforce shortages, develop innovative strategies to encourage and  
35 increase the recruitment and retention of health care, mental health  
36 care, direct support, and personal care professionals who are trained to  
37 provide 'care for' Alzheimer's 'disease' and 'related disorders or  
38 other forms of' dementia **'[care]'**, and take any other action  
39 necessary to encourage and facilitate the development and  
40 maintenance of a robust and specialized professional Statewide  
41 workforce that is capable of delivering high quality 'care for patients  
42 with' Alzheimer's 'disease' and **'[dementia-related care] related**  
43 **disorders or other forms of dementia'** to a rapidly growing population  
44 in the State; and

45 (8) study and make recommendations on any other issue related to  
46 Alzheimer's disease and related disorders or other forms of dementia.

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

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

8           (2) a description as to whether, how, and why the commission's  
9 findings have changed over time, including an indication as to the  
10 implementation status of the commission's prior recommendations, a  
11 description of actions that have been undertaken by any person or  
12 public or private entity in the State over the prior reporting period to  
13 implement those prior recommendations, and a description of the  
14 perceived or documented effects resulting from implementation of  
15 those prior recommendations;

16           (3) a copy of, or reference to, the statistical, demographic,  
17 testimonial, or other data or information that was used by the  
18 commission to: (a) support its current findings under paragraph (1) of  
19 this subsection; or (b) inform its analysis of the impact of the  
20 commission's prior recommendations under paragraph (2) of this  
21 subsection. The data provided pursuant to this paragraph shall be  
22 presented in aggregate form and shall not contain the **'[personally]**  
23 personal<sup>1</sup> identifying information of any patient, caregiver, or other  
24 person; and

25           (4) the commission's recommendations for legislative, executive,  
26 or other actions that can be undertaken, or strategies that can be  
27 implemented, to: (a) improve the quality, consistency, or affordability  
28 of care for<sup>1</sup> Alzheimer's disease<sup>1</sup> and related disorders or other  
29 forms of<sup>1</sup> dementia **'[care]**<sup>1</sup> in the State and ensure **'[its] the**<sup>1</sup>  
30 accessibility of care<sup>1</sup> to all who need it; (b) reduce, eliminate, or  
31 mitigate the societal and individual impact of, and the Statewide, local,  
32 and individual costs or financial burdens associated with, Alzheimer's  
33 disease and related disorders or other forms of dementia; (c) ensure  
34 that the State's professional workforce is adequately trained, is capable  
35 of providing affordable, high quality care for patients with<sup>1</sup>  
36 Alzheimer's disease<sup>1</sup> and related disorders or other forms of<sup>1</sup>  
37 dementia **'[care]**<sup>1</sup> throughout the State, and is sufficient in numbers  
38 and flexible enough to adapt to a rapidly increasing demand for  
39 services in the State; (d) ensure that unpaid caregivers in the State are  
40 recognized for their dedicated service and significant contributions to  
41 society and are provided with sufficient supportive and respite  
42 services, as well as financial assistance where possible and  
43 appropriate, as may be necessary for them to capably perform their  
44 caregiving tasks while avoiding unnecessary physical, mental, or  
45 financial strain; or (e) otherwise address the issues or mitigate the  
46 problems identified by the commission in its annual findings.

**S1033 [1R] VITALE**

12

- 1       4. P.L.2011, c.76 (C.26:2M-16 et seq.) is repealed.
- 2
- 3       5. This act shall take effect immediately.