

ASSEMBLY, No. 2682

STATE OF NEW JERSEY 220th LEGISLATURE

INTRODUCED FEBRUARY 14, 2022

Sponsored by:

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District 33 (Hudson)

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District 14 (Mercer and Middlesex)

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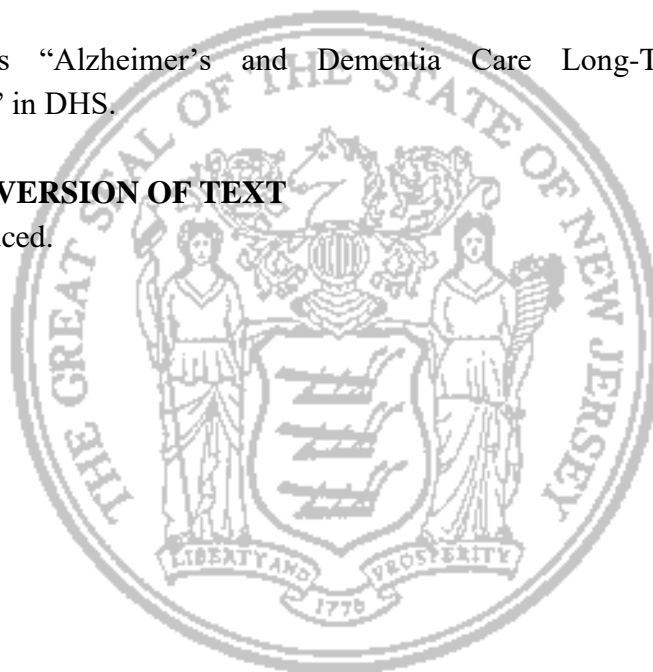
Assemblywomen Jaffer, Jasey, Reynolds-Jackson, Assemblymen DiMaio, DePhillips, Torrissi, Assemblywoman Chaparro, Assemblymen Umba, Verrelli, Assemblywoman Dunn, Assemblyman Calabrese, Assemblywoman Swift, Assemblyman McKeon, Assemblywoman McCarthy Patrick, Assemblymen Sauickie, Conaway, Assemblywoman DeFuccio, Assemblymen Peterson and S.Kean

SYNOPSIS

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

CURRENT VERSION OF TEXT

As introduced.



(Sponsorship Updated As Of: 2/13/2023)

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-
22 1 et seq.) and P.L.2011, c.76 (C.26:2M-16 et seq.) and the
23 establishment of two different study commissions thereunder, each
24 of those study commissions was temporary in nature and dissolved
25 after the 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 12 members, including:

1 (1) Three non-voting ex officio members or their designees as
2 follows: the Commissioner of Health, the Commissioner of Human
3 Services, and the New Jersey Long Term Care Ombudsman;

4 (2) two public members to be appointed by the President of the
5 Senate as follows: one who shall represent an organization that
6 advocates for members of the Alzheimer's community and one who
7 shall represent a for-profit healthcare facility that offers memory
8 care services;

9 (3) two public members to be appointed by the Speaker of the
10 General Assembly as follows: one who shall represent an
11 organization that advocates for members of the Alzheimer's
12 community and one who shall represent a non-profit healthcare
13 facility that offers memory care services ; and

14 (4) five public members to be appointed by the Governor as
15 follows: one geriatrician who shall currently be involved in the
16 provision of direct services to patients with Alzheimer's disease or
17 other related dementias one psychiatrist who shall provide
18 specialized services to persons with Alzheimer's disease or related
19 dementias; one caregiver who shall provide paid services to persons
20 with Alzheimer's disease or related dementias; one unpaid
21 caregiver of a family member who has Alzheimer's disease or a
22 related dementia; and one neurologist who provides specialized
23 services to persons with Alzheimer's disease or a related dementia.

24 c. Each public member of the commission shall serve for a
25 term of four years; however, of the public members first appointed,
26 two shall serve an initial term of one year, three shall serve an
27 initial term of two years, two shall serve an initial term of three
28 years, and two shall serve an initial term of four years. Each public
29 member shall serve for the term of their appointment and until a
30 successor is appointed and qualified, except that a public member
31 may be reappointed to the commission upon the expiration of their
32 term.

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

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

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

44 g. Each year, the commission shall meet pursuant to a schedule
45 to be established at its first annual meeting. The commission shall
46 additionally meet at the call of its chairperson or the Commissioners
47 of Health or Human Services. In no case shall the commission meet
48 less than four times per year.

1 h. A majority of the total number of members currently
2 appointed to the commission shall constitute a quorum. A vacancy
3 in the membership of the commission shall not impair the ability of
4 the commission to exercise its duties and effectuate its purposes.
5 The commission may conduct business without a quorum, but may
6 only vote on recommendations when a quorum is present.
7 Recommendations shall be approved by a majority of the members
8 present.

9 i. The members of the commission shall serve without
10 compensation, but shall be reimbursed for travel and other
11 miscellaneous expenses incurred in the necessary performance of
12 their duties, within the limits of funds made available to the
13 commission for its purposes.

14 j. The commission shall have the power to:

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

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

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

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

26 (5) enter into any and all agreements or contracts, execute any
27 and all instruments, and do and perform any and all acts or things
28 necessary, convenient, or desirable to further the commission's
29 purposes; and

30 (6) consult with, and solicit and receive testimony from, any
31 association, organization, department, agency, or individual having
32 knowledge of, and experience with: (a) the treatment and care of,
33 or provision of caregiving and personal care services to, persons
34 with Alzheimer's disease and other dementias; (b) the status or
35 quality of the State's professional workforce in relation to
36 Alzheimer's disease and dementia care; (c) the emotional, physical,
37 or financial effects of Alzheimer's disease and other dementias on
38 individuals, families, and the State; or (d) any other issues related to
39 Alzheimer's disease or dementia.

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

43

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

47 (1) study the incidence, prevalence, and impact of Alzheimer's
48 disease and related dementias in the State and in each region of the

1 State and make projections about the future Statewide and regional
2 incidence, prevalence, and impact of these conditions;

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

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

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

1 of, and improve their ability to more effectively address, issues
2 affecting persons with Alzheimer's disease or other dementias and
3 their families;

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

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

28 (7) evaluate the sufficiency of the State's Alzheimer's and
29 dementia care workforce, identify current and future workforce
30 needs, anticipate future workforce shortages, develop innovative
31 strategies to encourage and increase the recruitment and retention of
32 health care, mental health care, direct support, and personal care
33 professionals who are trained to provide Alzheimer's and dementia
34 care, and take any other action necessary to encourage and facilitate
35 the development and maintenance of a robust and specialized
36 professional Statewide workforce that is capable of delivering high
37 quality Alzheimer's and dementia-related care to a rapidly growing
38 population in the State; and

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

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

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

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

9 (3) a copy of, or reference to, the statistical, demographic,
10 testimonial, or other data or information that was used by the
11 commission to: (a) support its current findings under paragraph (1)
12 of this subsection; or (b) inform its analysis of the impact of the
13 commission's prior recommendations under paragraph (2) of this
14 subsection. The data provided pursuant to this paragraph shall be
15 presented in aggregate form and shall not contain the personally
16 identifying information of any patient, caregiver, or other person;
17 and

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

38
39 4. P.L.2011, c.76 (C.26:2M-16 et seq.) is repealed.

40
41 5. This act shall take effect immediately.

42
43
44 STATEMENT

45
46 This bill would permanently establish an "Alzheimer's and
47 Dementia Care Long-Term Planning Commission" in the Department
48 of Human Services (DHS) to provide for the ongoing evaluation of the

1 State's Alzheimer's disease and dementia care system and identify
2 means and methods that can be used to address significant
3 shortcomings in the system or otherwise expand and prepare the
4 system to meet the increasing and evolving needs of a rapidly aging
5 population.

6 The Alzheimer's and Dementia Care Long-Term Planning
7 Commission would consist of 12 members, including three non-voting
8 ex officio members, or their designees, as follows: the Commissioner
9 of Health, the Commissioner of Human Services, and the New Jersey
10 Long Term Care Ombudsman. The remaining eight members of the
11 committee are public member. The Speaker of the General
12 Assembly is to appoint two public members as follows: one who
13 shall represent an organization that advocates for members of the
14 Alzheimer's community and one who shall represent a for-profit
15 healthcare facility that offers memory care services. The President
16 of the Senate is to appoint two public members as follows: one who
17 shall represent an organization that advocates for members of the
18 Alzheimer's community and one who shall represent a non-profit
19 healthcare facility that offers memory care services. And finally,
20 the Governor is to appoint five public members as follows: one
21 geriatrician who is currently involved in the provision of direct
22 services to patients with Alzheimer's disease or other related
23 dementias; one psychiatrist who provides specialized services to
24 persons with Alzheimer's disease or related dementias; one
25 caregiver who provides paid services to persons with Alzheimer's
26 disease or related dementias; one unpaid caregiver of a family
27 member who has Alzheimer's disease or a related dementia; and
28 one neurologist who provides specialized services to persons with
29 Alzheimer's disease or a related dementia.

30 All initial appointments to the commission are to be made within
31 60 days after the bill's effective date, and the commission is to
32 organize as soon as practicable, but not later than the 30th day,
33 following the appointment of a majority of its members.

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

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

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

44 2) gather, analyze, and disseminate to health care professionals,
45 policymakers, and members of the public, as appropriate, various types
46 of data and information, as specified in the bill, related to Alzheimer's
47 and dementia care in the State and the needs of persons with
48 Alzheimer's disease and related dementias, the quality and

- 1 consistency of care that is provided to persons, including those
2 members of the medically underserved, poor, and lesbian, gay,
3 bisexual, transgender, questioning, queer, and intersex (LGBTQI)
4 communities, as well as the needs of their family members and
5 caregivers;
- 6 3) assess the availability and affordability of existing programs,
7 services, facilities, and agencies in the State that are used to meet the
8 needs of persons with Alzheimer's disease or other dementias and the
9 needs of their families and caregivers; evaluate the capacity of those
10 existing policies, programs, services, facilities, and agencies to adapt
11 to and adequately address the changing needs of dementia patients and
12 their families and caregivers in the face of a continually increasing
13 demand for services; and identify and recommend improvements to
14 existing policies, programs, services, facilities, or agencies or the
15 institution of new policies, programs, services, facilities, or agencies to
16 address unmet and expanding needs in this area;
- 17 4) study and outline the appropriate roles of State government,
18 local governments, and health care facilities and professionals in
19 providing or ensuring the provision of appropriate services and other
20 assistance to persons with Alzheimer's disease or related dementias,
21 including persons in early stages of disease, and in providing or
22 ensuring the provision of sufficient supportive and assistive services,
23 including training and respite services, to unpaid family caregivers;
24 and identify ways in which State and local governments and health
25 care systems could increase their awareness of, and improve their
26 ability to more effectively address, issues affecting persons with
27 Alzheimer's disease or other dementias and their families;
- 28 5) review and analyze the capacity of law enforcement officers
29 and emergency medical responders in the State to compassionately and
30 effectively interact with, diffuse conflicts involving, and provide
31 emergency services to, persons with Alzheimer's disease and related
32 dementias;
- 33 6) identify and recommend dementia-related best practices and
34 training requirements for: a) health care and mental health care
35 professionals, particularly geriatric specialists and primary care
36 practitioners, who are or will be practicing on the front lines of
37 Alzheimer's and dementia care; b) personal care professionals who
38 provide services to patients with Alzheimer's disease or related
39 dementias; and c) law enforcement officers, emergency medical
40 responders, and other public safety officers;
- 41 7) evaluate the sufficiency of the State's Alzheimer's and
42 dementia care workforce, identify current and future workforce needs,
43 anticipate future workforce shortages, develop innovative strategies to
44 encourage and increase the recruitment and retention of health care,
45 mental health care, direct support, and personal care professionals who
46 are trained to provide Alzheimer's and dementia care, and take any
47 other action necessary to encourage and facilitate the development and
48 maintenance of a robust and specialized professional Statewide

1 workforce that is capable of delivering high quality Alzheimer's and
2 dementia-related care to a rapidly growing population in the State; and

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

5 One year after the commission's organizational meeting, and
6 annually thereafter, the commission will be required to prepare and
7 submit a written report to the Governor and the Legislature. The
8 written report is to contain, at a minimum:

9 1) the commission's annual findings on the issues within the
10 commission's purview;

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

19 3) a copy of, or reference to, the de-personalized statistical,
20 demographic, testimonial, or other data or information that was used
21 by the commission either to support its current findings or inform its
22 analysis of the impact of the commission's prior recommendations;
23 and

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

44 In performing its duties under the bill, the commission would have
45 the power to:

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

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

- 1 3) solicit, receive, accept, and expend any grant moneys or other
2 funds that may be made available for its purposes by any government
3 agency or any private for-profit or not-for-profit organization or entity;
- 4 4) solicit and receive assistance and services from any State,
5 county, or municipal department, board, commission, or agency, as it
6 may require, and as may be available to it for its purposes;
- 7 5) enter into any and all agreements or contracts, execute any and
8 all instruments, and do and perform any and all acts or things
9 necessary, convenient, or desirable to further the commission's
10 purposes; and
- 11 6) consult with, and solicit and receive testimony from, any
12 association, organization, department, agency, or individual having
13 knowledge of, and experience with issues related to Alzheimer's
14 disease or other dementias.
- 15 The Department of Human Services would be required to provide
16 professional and clerical staff to the commission.