

SENATE, No. 1033

STATE OF NEW JERSEY
220th LEGISLATURE

INTRODUCED JANUARY 31, 2022

Sponsored by:

Senator JOSEPH F. VITALE

District 19 (Middlesex)

Co-Sponsored by:

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

SYNOPSIS

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

CURRENT VERSION OF TEXT

As introduced.



(Sponsorship Updated As Of: 5/9/2022)

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

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

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

45 e. In addition to burdening the person who suffers from the
46 disease, Alzheimer's disease and related disorders or other forms of
47 dementia place a tremendous and years-long burden on caregivers,
48 particularly family or other unpaid caregivers. These caregivers often

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

19 f. In 2019, more than 16 million caregivers provided an estimated
20 18.6 billion hours in unpaid assistance across the nation to persons
21 with Alzheimer’s disease and related disorders or other forms of
22 dementia – a contribution to the nation that is valued at \$244 billion,
23 which is equal to approximately 11 times the total revenue of
24 McDonald’s in 2018 . This included 448 caregivers who provided 510
25 million hours equal to \$6.6 billion worth of unpaid care in New Jersey
26 alone.

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

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

46 i. In 2019, total per-person health care and long-term care
47 payments from all sources for Medicare beneficiaries with
48 Alzheimer’s disease and related disorders or other forms of dementia

1 were \$50,201 per person for those with dementia and \$14,326 person
2 for those without dementia, which is over three times as great as
3 payments for other Medicare beneficiaries in the same age group.

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

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

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

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

35 n. There is currently a shortage of specialized geriatric
36 professionals in the State and nation to meet the needs of the rapidly
37 growing population of individuals aged 65 years or older and the
38 complex needs of aging individuals who are living with Alzheimer's
39 disease and related disorders or other forms of dementia . The
40 Alzheimer's Association *2020 Facts and Figures* report estimates that,
41 by 2030, an additional 23,750 geriatricians will be needed to meet the
42 needs of the aging population nationwide. In New Jersey, moreover,
43 the shortage of geriatricians is particularly great. As of 2019, the State
44 had only 205 geriatricians. The *2020 Facts and Figures* report
45 indicates that, by 2050, the State will need at least 398 geriatricians to
46 serve a mere 10 percent of the population aged 65 years or older and
47 will require a total of 1,193 geriatricians, representing a nearly six-fold
48 increase, to serve 30 percent of the population in this age 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 dementia
4 patients along the continuum of the disease and should, therefore, be
5 properly trained in identifying the warning signs of Alzheimer's
6 disease and related disorders or other forms of dementia , providing
7 timely and competent dementia diagnoses, and meeting the ongoing
8 care and support needs of patients who are living with dementia.

9 p. Although 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 this
13 area. These PCPs also reported a lack of access to sufficient dementia-
14 related training in medical schools and residency programs, and more
15 than half indicated that they had not pursued additional training in
16 dementia care following graduation or residency, due to challenges
17 associated with obtaining such supplemental training.

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

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

36
37 2. a. The Alzheimer's and Dementia Care Long-Term Planning
38 Commission is established in the Department of Human Services. The
39 purpose of the commission shall be to provide for the ongoing
40 evaluation of the State's Alzheimer's disease and dementia care
41 system and identify various innovative means and methods that can be
42 used to address the significant shortcomings in that care system and
43 otherwise expand and prepare the system to meet the increasing and
44 evolving needs of a rapidly aging population.

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

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

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

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

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

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

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

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

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

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

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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 necessary
11 expenses incurred in the performance of their duties, within the
12 limits of funds made available to the commission for its purposes.

13 j. The commission shall have the power to:

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

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

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

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

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

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

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

47 (1) study the incidence, prevalence, and impact of Alzheimer's
48 disease and related disorders or other forms of dementia in the State

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

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

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

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

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

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

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

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

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

46 b. One year after the commission's organizational meeting, and
47 annually thereafter, the commission shall prepare and submit a
48 written report to the Governor and, pursuant to section 2 of

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1 P.L.1991, c.164 (C.52:14-19.1), to the Legislature. The written
2 report shall contain, at a minimum:

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

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

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

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

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

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45 5. This act shall take effect immediately.

STATEMENT

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this bill would permanently establish an “Alzheimer’s and Dementia Care Long-Term Planning Commission” in the Department of Human Services (DHS) to provide for the ongoing evaluation of the State’s Alzheimer’s disease and dementia care system and identify means and methods that can be used to address significant shortcomings in the system or otherwise expand and prepare the system to meet the increasing and evolving needs of a rapidly growing population of individuals aged 65 years and older.

The Alzheimer’s and Dementia Care Long-Term Planning Commission would consist of 12 members, including three non-voting ex officio members, or their designees, including the Commissioner of Health, the Commissioner of Human Services, and the New Jersey Long Term Care Ombudsman, and nine public members.

The Speaker of the General Assembly is to appoint two public members, including one member who represents an organization that advocates for members of the Alzheimer’s community and one member who represents a for-profit healthcare facility that offers memory care services. The President of the Senate is to appoint two public members, including one member who represents an organization that advocates for members of the Alzheimer’s community and one member who represents a non-profit healthcare facility that offers memory care services.

The Governor is to appoint five public members as follows: one geriatrician provides direct services to patients with Alzheimer’s disease and related disorders or other forms of dementia; one psychiatrist who provides specialized services to persons with Alzheimer’s disease and related disorders or other forms of dementia; one caregiver who provides paid services to persons with Alzheimer’s disease and related disorders or other forms of dementia; one unpaid caregiver of a family member who has Alzheimer’s disease or a related disorder or other form of dementia; and one neurologist who provides specialized services to persons with Alzheimer’s disease and related disorders or other forms of dementia.

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

The commission will be required to meet each year pursuant to a schedule to be established at its first annual meeting. The commission will additionally be required to meet at the call of its chairperson or the call of the Commissioner of Health or the Commissioner of Human Services. In no case may the commission meet fewer than four times per year.

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

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- 1 1) study the incidence, prevalence, and impact of Alzheimer’s
2 disease and related disorders or other forms of dementia in the State
3 and in each region of the State and make projections about the
4 future Statewide and regional incidence, prevalence, and impact of
5 these conditions;
- 6 2) gather, analyze, and disseminate to health care professionals,
7 policymakers, and members of the public, as appropriate, various
8 types of data and information, as specified in the bill, related to
9 Alzheimer’s and dementia care in the State and the needs of persons
10 with Alzheimer’s disease and related disorders or other forms of
11 dementia, the quality and consistency of care that is provided to
12 persons, including those members of the medically underserved
13 community, the poor community, and the lesbian, gay, bisexual,
14 transgender, questioning, queer, and intersex (LGBTQI)
15 communities, as well as the needs of their family members and
16 caregivers;
- 17 3) assess the availability and affordability of existing programs,
18 services, facilities, and agencies in the State that are used to meet
19 the needs of persons with Alzheimer’s disease and related disorders
20 or other forms of dementia and the needs of their families and
21 caregivers; evaluate the capacity of those existing policies,
22 programs, services, facilities, and agencies to adapt to and
23 adequately address the changing needs of dementia patients and
24 their families and caregivers in the face of a continually increasing
25 demand for services; and identify and recommend improvements to
26 existing policies, programs, services, facilities, or agencies or the
27 institution of new policies, programs, services, facilities, or
28 agencies to address unmet and expanding needs in this area;
- 29 4) study and outline the appropriate roles of State government,
30 local governments, and health care facilities and professionals in
31 providing or ensuring the provision of appropriate services and
32 other assistance to persons with Alzheimer’s disease and related
33 disorders or other forms of dementia, including persons in early
34 stages of disease, and in providing or ensuring the provision of
35 sufficient supportive and assistive services, including training and
36 respite services, to unpaid family caregivers; and identify ways in
37 which State and local governments and health care systems could
38 increase their awareness of, and improve their ability to more
39 effectively address, issues affecting persons with Alzheimer’s
40 disease and related disorders or other forms of dementia and their
41 families;
- 42 5) review and analyze the capacity of law enforcement officers
43 and emergency medical responders in the State to compassionately
44 and effectively interact with, diffuse conflicts involving, and
45 provide emergency services to, persons with Alzheimer’s disease
46 and related disorders or other forms of dementia;
- 47 6) identify and recommend dementia-related best practices and
48 training requirements for: a) health care and mental health care

1 professionals, particularly geriatric specialists and primary care
2 practitioners, who are or will be practicing on the front lines of
3 Alzheimer's and dementia care; b) personal care professionals who
4 provide services to patients with Alzheimer's disease and related
5 disorders or other forms of dementia; and c) law enforcement
6 officers, emergency medical responders, and other public safety
7 officers;

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

19 8) study and make recommendations on any other issue related
20 to Alzheimer's disease and related disorders or other forms of
21 dementia.

22 One year after the commission's organizational meeting, and
23 annually thereafter, the commission will be required to prepare and
24 submit a written report to the Governor and the Legislature. The
25 written report is to contain, at a minimum:

26 1) the commission's annual findings on the issues within the
27 commission's purview;

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

36 3) a copy of, or reference to, the de-personalized statistical,
37 demographic, testimonial, or other data or information that was
38 used by the commission either to support its current findings or
39 inform its analysis of the impact of the commission's prior
40 recommendations; and

41 4) the commission's recommendations for legislative,
42 executive, or other actions that can be undertaken, or strategies that
43 can be implemented, to: a) improve the quality, consistency, or
44 affordability of Alzheimer's and dementia care in the State and
45 ensure its accessibility to all who need it; b) reduce, eliminate, or
46 mitigate the societal and individual impact of, and the Statewide,
47 local, and individual costs or financial burdens associated with,
48 Alzheimer's disease and related disorders or other forms of

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1 dementia; c) ensure that the State's professional workforce is
2 adequately trained, is capable of providing affordable, high quality
3 Alzheimer's and dementia care throughout the State, and is
4 sufficient in numbers and flexible enough to adapt to a rapidly
5 increasing demand for services in the State; d) ensure that unpaid
6 caregivers in the State are recognized for their dedicated service and
7 significant contributions to society and are provided with sufficient
8 supportive and respite services, as well as financial assistance
9 where possible and appropriate, as may be necessary for them to
10 capably perform their caregiving tasks while avoiding unnecessary
11 physical, mental, or financial strain; or e) otherwise address the
12 issues or mitigate the problems identified by the commission in its
13 annual findings.

14 In performing its duties under the bill, the commission would
15 have the power to:

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

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

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

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

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

31 6) consult with, and solicit and receive testimony from, any
32 association, organization, department, agency, or individual having
33 knowledge of, and experience with issues related to Alzheimer's
34 disease and related disorders or other forms of dementia.

35 The Department of Human Services will be required to provide
36 professional and clerical staff to the commission.