Senate Study Bill 3149 - Introduced

SENATE FILE _____
BY (PROPOSED COMMITTEE ON HUMAN RESOURCES BILL BY CHAIRPERSON RAGAN)

A BILL FOR

An Act relating to the state comprehensive Alzheimer's disease response strategy.

BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF IOWA:

Section 1. ALZHEIMER'S DISEASE RESPONSE STRATEGY —— FINDINGS AND INTENT.

1. The general assembly finds all of the following based on data compiled by the Alzheimer's association:

a. In 2011, an estimated 5.4 million Americans were diagnosed and living with Alzheimer's disease, the most common form of dementia. One in eight or 13 percent of people age 65 and older and 43 percent of people age 85 and older have Alzheimer's disease. With longer life expectancies and increases in the number of persons reaching 65 years of age, the number of new cases of Alzheimer's disease among those 65 years of age and older is expected to double by 2050, when someone in the United States will develop Alzheimer's disease every 33 seconds.

b. While the prevalence of Alzheimer's disease is greater among those over 65 years of age, younger onset Alzheimer's disease affects approximately 200,000 persons under age 65 nationwide. The impact can be financially devastating on the individuals and their families during their working years, and these individuals experience barriers to services and supports that are generally designed for an older population.

c. The impact of Alzheimer's disease is staggering in the emotional and economic toll on individuals, their families, and employers, in the increased loss of life, and in the costs of providing care.

(1) (a) Alzheimer's disease is a fatal condition with no known means to alter the underlying course of the disease. The symptoms of Alzheimer's disease worsen over time, slowly robbing individuals of their memories, autonomy, and, ultimately, life.

(b) Caregivers experience high levels of stress and negative effects on their health, employment, income, and financial security. In 2010, 14.9 million family and friends provided 17 billion hours of unpaid care to those with Alzheimer's and other dementias, at an estimated uncompensated

cost of $202.6 billion.

(c) In 2010, businesses lost $36.5 billion, including costs of lost productivity, related to employees providing care for individuals with Alzheimer's or other dementias.

(2) Alzheimer's disease is the sixth leading cause of death across all ages in the United States, and the fifth leading cause of death for those 65 years of age and older. While the major causes of death —— stroke, prostate cancer, breast cancer, heart disease, and HIV —— experienced significant declines between the years 2000 and 2008, deaths attributable to Alzheimer's have increased by 66 percent.

(3) Average Medicare payments for people with Alzheimer's disease and other dementias are three times higher than for those without the disease. Medicaid spending for seniors with Alzheimer's disease and other dementias is nine times higher than for those without the disease. Nursing home admissions are expected for 75 percent of those over 80 years of age with Alzheimer's disease, compared with only 4 percent of the general population.

d. In 2011, approximately 69,000 Iowans had been diagnosed with Alzheimer's disease, with an expected increase in its prevalence of 18 percent by the year 2025. Alzheimer's disease was the fifth leading cause of death for Iowans in 2009. In 2009, Iowans died from Alzheimer's at the rate of 42 deaths per 100,000, almost double the national average of 24.7 deaths per 100,000.

e. Iowa's challenge in confronting Alzheimer's disease is exacerbated by the state's large and growing aging population, fragmented service systems, lack of adequate disease data, and growing workforce shortage. In the 2011 listening sessions conducted by the Alzheimer's association, Iowans reported that the most critical issues associated with Alzheimer's are difficulty in obtaining a diagnosis, the need for training of physicians and other health care providers, more funding for federal research, the quality of care in facilities including

staffing ratios, activities, and turnover, and the availability and accessibility of services.

(1) By 2030, according to the United States Census Bureau, the population of Iowans 65 and older will constitute 22.4 percent of the state's total population.

(2) A fragmented service system results in difficulty for individuals and families in accessing information and resources, eligibility for services is often complicated and confusing, and while services are often developed to meet local needs this local flexibility means that services and supports are not consistently available across the state.

(3) (a) Workforce shortages and lack of training impact care for persons with Alzheimer's disease in day-to-day hands-on care, primary care, and specialty care.

(b) The inadequate capacity and insufficient training of the workforce requires enhancement of the geriatric competencies of the entire workforce and increased recruitment and retention of geriatric specialists and caregivers.

(c) It is estimated that direct care workers provide 70 to 80 percent of hands-on long-term care and personal assistance for the elderly, persons with disabilities, and persons with chronic conditions. The department of workforce development projects the need for an estimated 11,000 additional direct care professionals between 2008 and 2018.

(d) Sixty-two Iowa counties are designated as primary care shortage areas. Primary care practices are the initial point of diagnosis and information and ongoing care for many patients and their families. Lack of primary care practices delays response to patient needs and many clinicians have not received the specialized or state-of-the-art training specific to Alzheimer's disease.

(e) Ninety Iowa counties are mental health professional shortage areas. The specialty care areas most lacking in the state are psychiatry and neurology, two areas most needed by individuals with Alzheimer's disease.

f. Lack of understanding and misperceptions of Alzheimer's disease delay diagnosis and perpetuate the pervasive social stigma and feelings of isolation and denial about the disease, delay early assessment and diagnosis and access to accurate information and beneficial resources and services, and impede efforts to improve system supports for those with Alzheimer's. As many as 50 percent of people meeting the diagnostic criteria for dementia have never received a diagnosis. While there is not a known cure for Alzheimer's disease, early detection affords the benefits of better management of symptoms, behaviors, and coexisting conditions; facilitation of a course of care; provision of training, education, and support services; delay in progression of the disease and potential institutionalization; and opportunity for advance planning for the future.

g. (1) Transformation must take place in the way individuals with Alzheimer's and their families are perceived and supported; in the way medical and long-term care is provided and managed; and in the way communities prepare for the challenge of a growing number of Iowans touched by Alzheimer's.

(2) Alzheimer's disease is one of the greatest public health challenges facing the current generation and requires a comprehensive state response to provide persons with Alzheimer's disease, their families and caregivers, health and long-term care providers, and society as a whole with a strategy to confront this personally devastating and publicly costly crisis.

2. It is the intent of the general assembly that the comprehensive Alzheimer's disease response strategy incorporate all of the following principles:

a. Build the foundation to prepare for long-term investments and comprehensive supports in the future. This principle includes addressing the stigma of the disease, collecting useful data, addressing workforce challenges, and

creating a state-level infrastructure to prepare the state for the future.

b. Recognize that Alzheimer's disease and related dementias are best addressed with a social model of supports, rather than a medical model of treatment. The social model incorporates strategies such as delaying onset of the disease through healthy behaviors, improving long-term health, and providing psychosocial supports and education for individuals and their families.

c. Expand partnerships between public and private entities with interest or expertise in Alzheimer's disease, and efficiently utilize services within limited resources and funding. Partnerships should include but are not limited to federal, state, and local governments; community-based, nonprofit, faith-based, health care, long-term care, and other organizations; and other interested individuals and entities.

d. Endeavor to provide standardized and consistent access to multiple, individualized services and supports. Initial efforts should focus on providing access to information and referral sources, and to home and community-based services.

e. Invest in evidence-based interventions. There are proven interventions for Alzheimer's disease, and the state should use its limited resources to target proven strategies.

Sec. 2. NEW SECTION. **135P.1 Definitions.**

As used in this chapter, unless the context otherwise requires:

1. *"Alzheimer's disease"* or *"Alzheimer's"* means a progressive, degenerative, fatal disorder that results in loss of memory, loss of thinking and language skills, and behavioral changes. *"Alzheimer's disease"* includes related dementias including vascular dementia, Parkinson's disease, dementia with Lewy bodies, frontotemporal dementia, Crutzfeldt-Jakob disease, normal pressure hydrocephalus, and mixed dementia.

2. *"Department"* means the department of public health.

Sec. 3. NEW SECTION. **135P.2 Comprehensive Alzheimer's**

disease response strategy —— coordination hub, development, and administration of strategy.

1. The department of public health shall coordinate the state's efforts to administer a comprehensive Alzheimer's disease response strategy including provision of a coordination hub to facilitate, integrate, deliver, and monitor interagency planning and policymaking; education, training, and public awareness protocols and activities; provision of public information and referral services; public and private partnerships; and funding resources.

2. The department shall build a foundation to prepare for long-term investments in and support of a comprehensive strategy. In building this foundation, the department shall expand partnerships between public and private entities with interest or expertise in Alzheimer's disease; emphasize a social model of supports rather than a medical model of treatment; increase public awareness and address the stigma of the disease; develop a system of standardized and consistent access to multiple, individualized, and least restrictive quality services and supports; provide access to information and referral sources; address workforce challenges; collect and disseminate useful data; and invest in evidence-based interventions.

3. The department shall formulate a multiyear comprehensive Alzheimer's disease response strategy to address Alzheimer's disease that includes short-term and long-term objectives. Both short-term and long-term objectives should focus on providing individuals with Alzheimer's disease with the highest quality care in the most efficient manner at all stages of the disease and in all settings across the service and supports continuum. The department shall update the initial strategy as necessary to address the challenges presented with increased prevalence of the disease and shall submit a progress report annually in January to the governor and the general assembly.

4. In administering the comprehensive Alzheimer's

disease response strategy, the department shall do all of the following:

a. Infrastructure. The department shall create the coordinated state infrastructure necessary to support and fund Alzheimer's disease-related activities in the state.

(1) The department shall establish the position of Alzheimer's coordinator within the department to work in partnership with public and private entities and the multidisciplinary advisory council to formulate and administer the comprehensive Alzheimer's disease response strategy, to avoid duplication of public and private efforts, and to leverage and efficiently utilize available funding and resources. The coordinator shall do all of the following:

(a) In collaboration with the multidisciplinary advisory council, initially formulate and subsequently update the comprehensive Alzheimer's disease response strategy.

(b) Coordinate a public awareness campaign with public and private partners.

(c) Lead and coordinate data collection efforts among public and private entities, and disseminate pertinent information.

(d) Promote Alzheimer's disease evidence-based practices, including but not limited to caregiver education and training and physician practice standards.

(e) Act as a liaison to the aging and disability resource centers, area agencies on aging, state and national Alzheimer's association chapters, and other entities to ensure Alzheimer's disease is appropriately addressed statewide.

(f) Monitor relevant workforce projections and workforce enhancement activities in coordination with the department of workforce development, the health and long-term care advisory council created pursuant to sections 135.163 and 135.164, and other existing entities and efforts.

(g) Research, respond to, and coordinate funding opportunities, including promotion of public-private

partnerships.

(h) Create accountability among public and private entities responsible for providing services and supports for individuals with Alzheimer's disease and their families.

(i) Act as the state-level Alzheimer's disease expert to build and maintain relationships at the local, state, and national levels.

(j) Provide staff support to the multidisciplinary advisory council.

(2) The department shall create a multidisciplinary advisory council to assist and advise the department and the coordinator, to develop partnerships to coordinate, collaborate, and support Alzheimer's-related services and programs throughout the state, and to advocate on behalf of persons with Alzheimer's and their families. The department and coordinator may establish workgroups of the advisory council as necessary to administer the response strategy. The advisory council shall include but is not limited to representation from all of the following:

(a) Individuals with Alzheimer's disease and their families.

(b) Caregivers and other consumers with an interest in Alzheimer's disease.

(c) Adult day services, respite, and other home and community-based services.

(d) Primary care providers.

(e) Geriatricians, neurologists, and other specialty care providers with expertise in Alzheimer's disease.

(f) Nursing facilities, assisted living programs, and other facility-based services.

(g) Hospitals, clinics, and other medical facilities.

(h) The Alzheimer's association, Iowa chapter.

(i) The Iowa caregivers association.

(j) AARP Iowa.

(k) The Iowa association of area agencies on aging.

(l) The long-term care resident's advocate.

(m) Faith-based entities.

(n) Community-based organizations with an interest in Alzheimer's disease.

(o) The department on aging.

(p) The department of human services.

(q) The department of inspections and appeals.

(r) The department of public safety.

(s) The department of workforce development.

b. Awareness and education.

(1) The department shall administer a public awareness and education campaign to demystify and encourage public understanding and acceptance of Alzheimer's disease, promote the importance of early detection and diagnosis, educate physicians and other health professionals in best practice standards for care of persons with Alzheimer's, and disseminate accurate information and promote available resources.

(2) The campaign shall educate the public about the true prevalence of the disease, its social and economic impact on families, government, and society, signs and symptoms of cognitive problems in general and Alzheimer's disease specifically, how health care professionals should screen, diagnose, and treat cognitive problems, services and supports available, and the need for funding for research and services.

(3) The campaign shall target education to physicians and other health care professionals to promote best practices in diagnosis and referral, to increase early intervention and diagnosis, and to provide more immediate access to information and support for newly diagnosed individuals and their families.

(a) The campaign shall explore, endorse, and disseminate dementia-specific curriculum and training programs tailored to primary care providers to strengthen the role of primary care providers in assessing, treating, and supporting individuals with Alzheimer's disease.

(b) The department may utilize existing professionally

developed performance measures, such as the dementia performance measurement set developed by the physician consortium for performance improvement, in assisting physicians and other health care professionals in improving the quality of care for persons with Alzheimer's disease. Such performance measures may include but are not limited to activities such as performing cognitive assessments, determining functional status, managing symptoms, conducting palliative care counseling and advance care planning, and providing caregiver education and support.

c. Providing information and resources to persons with Alzheimer's and their families. The department shall create statewide partnerships to utilize and expand existing information and referral, education, care planning, and care coordination services to promote consumer access to quality information and services and to provide guidance and support to individuals with Alzheimer's and their families throughout the continuum of the disease. Partners may include but are not limited to the Alzheimer's association, Iowa chapter, and the aging and disability resource centers. The department shall ensure that any information or referral sources utilized are dementia-capable and provide accurate, reliable information. The efforts shall include educating community networks about Alzheimer's disease information and referral sources. The department shall integrate the participation of appropriate sectors of the community including but not limited to health care, public safety, legal system, and others in addressing the needs of and providing a coordinated network of support for individuals with Alzheimer's and their families.

d. Addressing workforce challenges. The department shall endeavor to ensure that individuals with Alzheimer's disease receive appropriate, quality care and treatment by professionals and caregivers who are Alzheimer's disease proficient and competency-based trained. The department shall work to expand and enhance the available and adequately

educated and trained workforce necessary to address the needs of people with Alzheimer's disease. The department shall define the elements of quality Alzheimer's care, determine the best indicators to measure whether quality care is being delivered, and embed these measures throughout every level of the medical and long-term care delivery systems to drive better practice.

(1) The department shall invest in state-level efforts to improve recruitment and retention of targeted professionals, including but not limited to psychiatrists, gerontologists, neurologists, and direct care professionals.

(2) The department shall coordinate with other state efforts to align and implement curriculum recommendations and dementia training requirements for direct care professionals and to expand application of a curriculum to other professionals and service providers who interact with persons with Alzheimer's disease. The department shall specifically incorporate into the goal of addressing workforce challenges, the directives relating to services, training, education, and public awareness for providers of services and supports as provided pursuant to section 231.62, Code Supplement 2011, to create dementia care protocols for facilities, agencies, and individuals that provide services and supports to individuals with Alzheimer's disease.

e. Increasing access to quality services. The department shall assess and identify gaps in the supply and adequacy of services and supports across the continuum of home and community-based, residential, medical, and social services and supports to address the needs of individuals with Alzheimer's and their families.

(1) The department shall promote coordinated, interdisciplinary, team-based, and person-centered care across the spectrum of medical, social, home and community-based, and long-term care to address the numerous facets of Alzheimer's disease and to ease transitions for individuals in the

progression of the disease.

(2) In developing the system of care, the department shall use and promote the availability of concepts and characteristics such as the health home and preventive care; promote and expand the availability of home and community-based services and supports including but not limited to respite and adult day services; expand the utilization of technologies such as telemedicine that increase access to services for persons with Alzheimer's, especially in rural and underserved areas of the state; and promote improvements in the capacity of residential levels of care to provide dementia-capable quality care for individuals with Alzheimer's disease.

(3) The department shall promote equitable access to affordable, necessary services and supports that are universally available, and delivered by dementia-capable providers.

f. Improving Alzheimer's disease data collection in the state. The department shall increase surveillance of the prevalence of Alzheimer's disease and its social, economic, and personal impact in the state to develop a source of reliable, quantifiable data.

(1) The department shall review, and to the extent possible, utilize existing assessment tools to promote common data elements and uniform collection of data to accurately capture relevant data on the population of persons with Alzheimer's disease in the state. Data collection shall focus on enabling better identification of Iowans with Alzheimer's disease, planning for services and efficient use of funding, and supporting research on the disease.

(2) The department shall also collect data to identify the unique needs and issues of persons with Alzheimer's disease who experience younger onset, and develop a plan to address the needs of this population.

(3) The department shall specifically incorporate the analysis of service utilization and future service needs as

directed in section 135.171, Code 2011.

(4) The department shall act as a centralized point of data collection and serve as a clearinghouse of information to assist individuals with Alzheimer's, their families, caregivers, policymakers, and others with interest in Alzheimer's disease.

Sec. 4. REPEAL. Sections 135.171 and 231.62, Code and Code Supplement 2011, are repealed.

EXPLANATION

This bill relates to the state's response strategy for Alzheimer's disease.

The bill provides findings and the intent of the general assembly regarding Alzheimer's disease. The findings include national prevalence data; data regarding the individual, social, and economic impact of Alzheimer's; and data specific to Alzheimer's disease in this state.

The bill provides that it is the intent of the general assembly that the comprehensive Alzheimer's disease response strategy incorporate the principles of building the foundation to prepare for long-term investments and comprehensive supports in the future; recognize that Alzheimer's disease and related dementias are best addressed with a social model of supports, rather than a medical model of treatment; expand partnerships between public and private entities with interest or expertise in Alzheimer's disease, and efficiently utilize services within limited resources and funding; endeavor to provide standardized and consistent access to multiple, individualized services and supports; and invest in evidence-based interventions.

The bill creates a new Code chapter, Code chapter 135P, to provide for a comprehensive Alzheimer's disease response strategy. The bill provides a definition of Alzheimer's disease which includes related dementias.

The bill directs the department of public health (DPH) to coordinate the state's efforts to administer a comprehensive Alzheimer's disease response strategy and to build a foundation

to prepare for long-term investments in and support of a comprehensive strategy. The department is directed to formulate a multiyear comprehensive Alzheimer's disease response strategy with short-term and long-term objectives, to update the strategy as necessary, and to submit a progress report annually in January to the governor and the general assembly.

The elements of the comprehensive Alzheimer's disease response strategy relate to infrastructure, which includes the establishment within the department of the position of Alzheimer's coordinator and creation of a multidisciplinary advisory council; increased awareness and education of the public and health care providers; provision of information and resources to persons with Alzheimer's and their families; addressing workforce challenges; increasing access to quality services across the continuum; and improving data collection on Alzheimer's in the state.

The bill repeals the Code section relating to a directive to DPH to analyze Iowa's population to determine the existing service utilization and future service needs of persons with Alzheimer's disease and similar forms of irreversible dementia (Code section 135.171) and the Code section relating to a directive to the department on aging to review trends and initiatives to address the long-term living needs of Iowans with Alzheimer's disease and similar forms of irreversible dementia, and to expand and improve training and education of persons who regularly deal with persons with Alzheimer's disease and similar forms of irreversible dementia (Code section 231.62). Both of these directives are instead incorporated into the duties of DPH under the new Code chapter.