



Connecticut General Assembly

# Report of the Task Force on Alzheimer's Disease and Dementia

Special Act 13-11: An Act Establishing a Task Force on Alzheimer's Disease and Dementia

## Table of Contents

I.	Executive Summary.....	Page 3
II.	Membership & Process Overview.....	Page 7
III.	Background.....	Page 10
IV.	Findings and Recommendations.....	Page 19
V.	Appendix:	
	A. 10 Warning Signs and 7 Stages of Alzheimer’s.....	Page 32
	B. Recommended Tiers for Workforce Education and Development.....	Page 33
	C. Connecticut Programs and Community Resources.....	Page 34
	D. Relevant Statutes and Regulations.....	Page 42

## Executive Summary

Alzheimer's disease is an irreversible, progressive brain disease that affects over 5 million Americans. It slowly destroys brain function, leading to cognitive decline (e.g., memory loss, language difficulty, poor executive function), behavioral and psychiatric disorders (e.g., depression, delusions, agitation), and declines in functional status (e.g., ability to engage in activities of daily living and self-care). It is one of the most feared diseases.

In Connecticut, it is estimated there are over 70,000 individuals age 65 and older living with Alzheimer's disease or another dementia. Unless the disease can be effectively treated or prevented, the number will increase significantly in the next two decades.

In more than 90 percent of people with Alzheimer's disease, symptoms do not appear until after age 60, and the incidence of the disease increases with age. The causes of Alzheimer's disease are not completely understood, but researchers believe they include a combination of genetic, environmental, and lifestyle factors. In rare cases, known as early or younger-onset, people develop symptoms in their 30s, 40s, or 50s. A significant number of people with Down syndrome develop dementia in their 50s.

Alzheimer's disease places enormous emotional, physical, and financial stress on individuals and their family members. Informal caregivers, such as family members and friends, provide the majority of care for people with Alzheimer's disease in the community. In Connecticut, family and friends provide an estimated \$2.4 billion in unpaid care to individuals living with Alzheimer's and other dementias. The intensive support required for a person with Alzheimer's disease can negatively impact the caregiver's emotional and physical health. Informal caregivers often report symptoms of depression and anxiety, and have poorer health outcomes than their peers who do not provide such care. Additionally, Connecticut's aging population and rebalancing initiatives toward home and community-based services will increase demand for paid direct care workers employed in community-based settings. Particularly, the demand for personal care attendants and home health aides is projected to increase substantially.

Dementia care costs are significant and are often a burden to families providing unpaid care. Caring for people with Alzheimer's disease also strains health and long-term care systems. For instance, individuals with the disease are hospitalized 2 to 3 times as often as people in the same age group who do not have the disease, and almost 70% of nursing home residents have a cognitive impairment. As the number grows, the disease will place a major strain on these care systems as well as on Medicare and Medicaid, major funders of this care.

The task force studied the care and services provided to persons diagnosed with Alzheimer's disease and dementia in the state. Based on the need to develop a state strategy to address and prepare for the escalating public health crisis, these findings and recommendations focus on strategies to increase public awareness, early detection and diagnosis of the disease, address gaps in quality of care- by building a capable workforce through dementia specific training. The recommendations also

provide a guide to improve the quality of life for those affected by dementia, and minimizing the associated public and private costs through better case management of the disease.

The Task Force is cognizant of the establishment of the National Alzheimer's Project Act (NAPA) by President Obama in 2011 and the goals and objectives pursuant to this legislation as iterated in the first National Plan to Address Alzheimer's Disease released in 2012. The Task Force embraces the key tenets of this Plan to address the areas of coordinated research and services, the development of treatments to prevent, halt, or reverse the course of the disease, early diagnosis and coordination of care, and improved outcomes for ethnic and racial minority populations that are at higher risk for Alzheimer's disease.

Given the slow improvements in Connecticut's economy, the recommendations primarily focus on short-term goals that can be undertaken in the next three to five years. While long-term innovations will need to be created with demand, the task force attempted to develop recommendations that expand or improve systems already in place where possible. In addition, it is important to recognize the vital role varied professionals, local municipalities, and the private sector play in achieving the capacity to effectively respond and address the care and service needs of individuals and families affected by Alzheimer's and dementia.

### **Priority Recommendations**

#### **Promote public awareness and best practices in diagnosing Alzheimer's and dementia to connect those with Alzheimer's and their caregivers to available resources.**

- Create a public/community awareness campaign through partnerships, including, but not limited to, the Alzheimer's Association, AARP, State Department on Aging, Area Agencies on Aging, faith-based and immigrant communities, business/corporate associations, chambers of commerce, medical community and professional/trade associations to increase community and family awareness of resources, including the Alzheimer's Association Help Line and 211.
- Disseminate informational packets to be distributed at doctors' offices, pharmacies, senior centers and other locations for individuals diagnosed with Alzheimer's disease and caregivers. Much of this information is available through the Alzheimer's Association.
- Promote Medicare Annual Wellness visits which include a cognitive impairment assessment for early detection and diagnosis, but is often not conducted in the visit.
- Cognitive impairment poses the most significant risk for exploitation. Develop a bank reporting project that includes bank reporting training programs. Bank personnel may be in a unique position to detect financial exploitation of older adults and individuals with dementia. Employees should be trained about potential red flags that indicate suspicious activity. Potential red flags include: Recent changes to a person's will, misuse of Power of

Attorneys, unusually high levels of activity or out-of-state charges. Banks should have immunity after reporting and addressing suspicious activity.

### Increase support for informal caregivers who provide care for persons with dementia.

- Develop an affordable “train the trainer” dementia course based on the existing Alzheimer’s Association caregiver support group leaders’ training. Develop a model similar to the American Red Cross’ CPR training program, whereby trained educators could then offer accessible and affordable dementia education to caregivers or others in the community.
- Support and enhance rebalancing initiatives that focus on diversion of individuals with dementia who are at risk of nursing home placement to community-based settings.
  - Increase funding to expand the CT Statewide Respite Care Program to reflect the growing demand. **(Fiscal impact)**
  - Expand and set aside slots for individuals with younger onset Alzheimer’s disease in the Connecticut Home Care Program for the Disabled. **(Fiscal impact)**
  - Adult Day Care represents an option that prevents isolation and can delay or completely divert individuals from nursing facilities. Due to limited and diminishing reimbursements, several of Connecticut’s Adult Day Centers are reducing services or closing. Ensure Adult Day Centers remain a viable community care option by increasing the current reimbursement level to meet operating costs based on level of care provided (e.g. medical model requires nurses, aides and medication/health monitoring). Daily rate should include transportation costs. Reimbursements should be adjusted annually to reflect Cost of Living Adjustments. **(Fiscal impact)**
- To minimize family disputes, ensure that the wishes of the individual are known and respected, and avoid costly court proceedings, encourage financial planning (including assessment of assets) and advanced directives with the help of an attorney with specific knowledge in elder, probate or estate law.
- Ensure coordination and connection to support services after diagnosis including: a checklist of next steps, identification of a care coordinator, and use of an integrated care model. Explore federal funding for research and demonstrations to achieve this goal. The 2010 Affordable Care Act is providing for time-limited innovation and demonstration projects that could result in new information about the cost-effectiveness of Alzheimer’s and dementia treatments and care practices centered around care coordination and transitional care models. Support CT’s existing initiatives such as the State Innovation Model (SIM) and Medicare and Medicaid Enrollees Care Coordination Demonstration and encourage focused efforts on individuals with dementia.

### Enhance Care Quality

- Study the financial impact of developing a Dementia Centers for Excellence (COE) or geriatric assessment units (GAU) at CT hospitals.

- The Department of Social Services developed the Interagency Referral Form (W10) to serve as physicians' orders for diagnoses, medications, treatments, recent immunizations, and allergies, as well as demographic information. The one-page form or an electronic version of the form developed by the facility is used by hospitals, nursing facilities and home care agencies to communicate essential care information for patient well-being. The Departments of Social Services and Public Health shall update the Interagency Referral Form (W10) to include a person-centered dementia care profile for pain management, wandering history, safety issues and behavioral triggers and reactions, or reflect other dementia care vulnerabilities and history. The form shall be used across the continuum of care providers. **(May require legislation)**
- There are few Alzheimer's and dementia training requirements for health care professionals and facilities serving individuals with Alzheimer's disease and dementia in Connecticut. Currently only "special care units" require dementia-specific training for staff. Connecticut's aging population and rebalancing initiatives towards home and community based services will increase demand for direct care workers employed in community-based settings such as home health aides, homemakers and companions and personal care assistants. See page 29 for detailed recommendations for dementia- specific training requirements across the continuum of care. **(Requires legislation)**
- Increase connectivity and training opportunities for the home and community based direct care workforce by utilizing emerging high tech training and education models.
- Integrate and continue basic level of dementia training and education for public safety responders, long-term care ombudsman, protective service employees, probate judges and court personnel. Expand annual missing persons police force training to include dementia education (CGS § 7-294o). **(May require legislation)**
- Require mandatory dementia-specific training for hospital emergency room staff, including nurses, physicians and medical technicians. **(May require legislation)** Build upon the existing collaboration between the Alzheimer's Association- CT Chapter and the CT Hospital Association.

This report frequently uses the term "Alzheimer's" or "Alzheimer's disease and related dementias" interchangeably in referring to Alzheimer's disease and related dementias. Related dementias include frontotemporal, Lewy body, mixed, and vascular dementia.

## Task Force Membership

Special Act 13-11, An Act Establishing a Task Force to Study Alzheimer's Disease and Dementia, established a task force to study issues related Alzheimer's Disease and Dementia.

Task Force members are:

Representative Joseph Serra, Task Force Co-Chair, Co-Chair Aging Committee

State Department on Aging Commissioner Edith Prague, Task Force Co-Chair

Senator Terry Gerratana, Co-Chair Public Health Committee

Representative Susan Johnson, Co-Chair Public Health Committee

Senator Andres Ayala, Co-Chair Aging Committee

Representative Prasad Srinivasan, Ranking Member Public Health Committee

Senator Kevin Kelly, Ranking Member Aging Committee

Pamela Atwood  
appointed by House Minority Leader Lawrence Cafero

Kathleen Brennan  
Deputy Commissioner, Department of Social Services

Honorable Daniel Caruso  
Probate Court Administrator designee

Eileen Cleary  
appointed by House Majority Leader Joe Aresimowicz

Dr. Leo Cooney  
appointed by Senate Majority Leader Martin Looney

Dr. Paulo Correa  
appointed by Senator Jason Welch, Ranking Member Public Health Committee

Cynthia Grant  
State Department on Aging designee

David Guttchen  
Chair of the Long-Term Care Planning Committee

Lori Griffin  
Department of Public Health designee

Lakisha Hyatt  
Department of Developmental Services designee

Laurie Julian  
appointed by Senate Minority Leader John McKinney

Nancy Leonard  
appointed by Senate President Donald E. Williams, Jr.

Kathy Marioni  
Department of Labor designee

Kelly Smith Papa  
appointed by Representative Al Adinolfi, Ranking Member Aging Committee

Sandra A. Pniewski  
appointed by Governor Dannel P. Malloy

James Thomas  
Department of Emergency Services and Protection designee

Kathleen Titsworth  
Department of Banking designee

Sid Yudowitch  
appointed by Speaker of the House Brendan Sharkey

**Administrative Support:**

Deb Migneault, Senior Policy Analyst, Connecticut's Legislative Commission on Aging



## Process Overview

The following report is the culmination of four months of work of the Alzheimer's Disease and Dementia Task Force. In accordance with Special Act No. 13-11 the task force was charged with studying the following:

- (1) Services provided to persons diagnosed with Alzheimer's disease and dementia, including persons with early-stage and early-onset of Alzheimer's disease, and such persons' family members and caregivers;
- (2) legislative policy changes to better serve such persons, family members and caregivers;
- (3) coordination between state agencies and private community-based health care providers to serve such persons, family members and caregivers;
- (4) case management services for such persons, family members and caregivers;
- (5) the transition of such persons from one health care facility to another;
- (6) the placement of such persons in community-based settings or health care facilities other than nursing home facilities, where feasible.

The Act requires the task force to report its findings and recommendations, including any recommendations for legislation, to the legislature by January 1, 2014.

### **Activities and Deliberations of the Task Force to Study Alzheimer's Disease and Dementia**

The Task Force met six (6) times between September and December 2013. In order to thoroughly study and articulate the findings, the Task Force created three sub-committees to address the following areas:

- 1) Early Detection, Intervention and Planning: Lakisha Hyatt, Chairperson
- 2) Quality Care, Service Delivery and Care Management: Pam Atwood, Chairperson
- 3) Workforce Training and Development: Kelly Smith Papa, Chairperson

Each sub-committee met 4-6 times from October through December 2013 and reported their findings and recommendations to the full task force.

All agendas, audio and CT-N coverage when available can be found on the Legislative Commission on Aging website at [www.cga.ct.gov/coa](http://www.cga.ct.gov/coa). Questions regarding the activities and accomplishments of the Task Force can be directed to Deb Migneault at the Commission on Aging by phone at (860) 240-5200 or email at [deborah.migneault@cga.ct.gov](mailto:deborah.migneault@cga.ct.gov) or Laurie Julian at the Alzheimer's Association at (860) 828-2828 or email [ljulian@alz.org](mailto:ljulian@alz.org).

## Background

### **Alzheimer's Disease and Dementia - What is Alzheimer's?**

Dementia is an umbrella term describing a variety of diseases and conditions that develop when nerve cells in the brain die or no longer function normally. Different types of dementia are associated with distinct symptom patterns and brain abnormalities; such as Dementia with Lewy bodies, Vascular dementia, Frontotemporal lobar degeneration, Parkinsons Disease, etc. Alzheimer's is the most common type of dementia. Alzheimer's disease causes problems with memory, thinking and behavior.

Alzheimer's progresses over time and can affect different people in different ways, but the most common symptom pattern begins with gradually worsening difficulty in remembering new information. (Appendix A) Individuals progress from mild Alzheimer's to moderate and severe disease at different rates. Cognitive and functional abilities decline as the disease progresses. Common early symptoms include repeating questions and comments, relying more on notes and calendars, misplacing things, struggling with names and getting lost driving. Behavioral changes are also common and may include irritability, apathy, aggression, agitation and depression. Wandering occurs in over sixty percent of cases. In advanced Alzheimer's, individuals need help with basic activities of daily living, such as bathing, dressing, using the bathroom and eating. Those in the final stages of the disease may lose their ability to communicate, fail to recognize loved ones and are reliant on caregivers for basic human needs around-the-clock. Alzheimer's disease is ultimately fatal.

The greatest risk factor for Alzheimer's disease is advancing age, but Alzheimer's is not a normal part of aging. Most people with Alzheimer's disease are diagnosed at age 65 or older. However, people younger than age 65 can also develop the disease. When Alzheimer's develops in a person younger than age 65, it is referred to as "younger-onset" (or "early-onset") Alzheimer's. Family history and genetics are also risk factors.

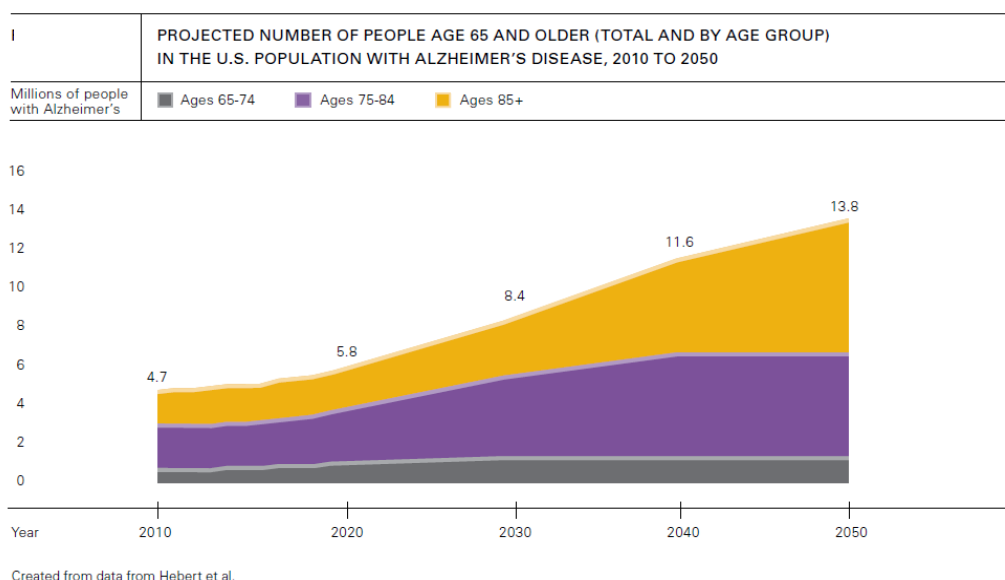
Currently, there is no cure or treatment for Alzheimer's and no way to stop the underlying death of brain cells. But drugs and non-drug treatments may help with both cognitive and behavioral symptoms.

### **Prevalence**

Over 5 million Americans of all ages have Alzheimer's in 2013. This includes an estimated 5 million people age 65 and older and approximately 200,000 individuals under age 65 who have younger-onset Alzheimer's.

- One in nine people age 65 and older (11 percent) has Alzheimer's disease.
- About one-third of people age 85 and older (32 percent) have Alzheimer's disease.
- Of those with Alzheimer's disease, an estimated 4 percent are under age 65, 13 percent are 65 to 74, 44 percent are 75 to 84, and 38 percent are 85 or older. (2013 *Alzheimer's Disease Facts and Figures*)

The number of Americans surviving into their 80s, 90s and beyond is expected to grow dramatically due to advances in medicine and medical technology, as well as social and environmental conditions. Additionally, a large segment of the American population, the baby boom generation, has begun to reach the age range of elevated risk for Alzheimer’s and other dementias. By 2030, the segment of the United States population age 65 and older is expected to grow dramatically, and the estimated 72 million older Americans will make up approximately 20 percent of the total population (up from 13 percent in 2010). As the number of older Americans grows rapidly, so too will the numbers of new and existing cases of Alzheimer’s disease.



In Connecticut there are an estimated 70,000 individuals over 65 with Alzheimer’s or other dementias. This number is projected to increase.

//////

**NUMBER OF PEOPLE AGED 65 AND OLDER WITH ALZHEIMER’S BY AGE** *Totals may not add due to rounding.*

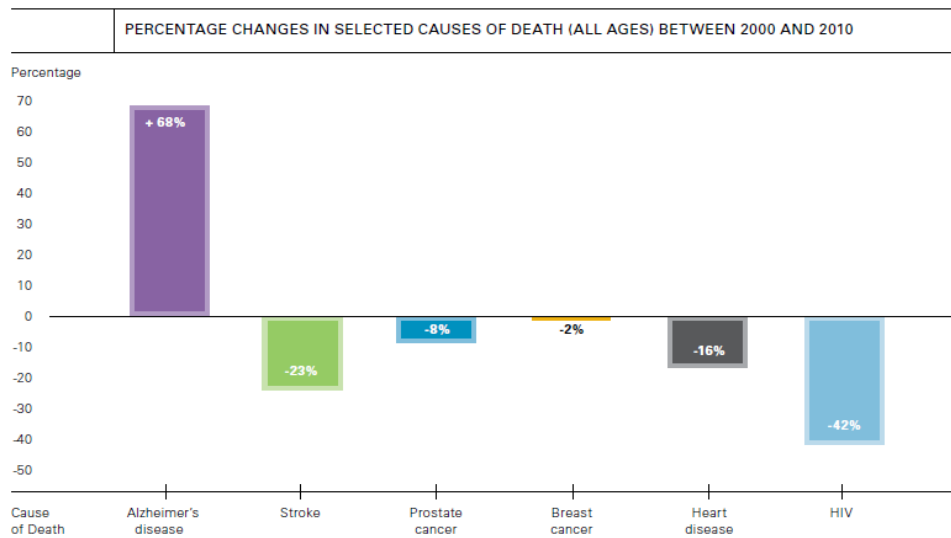
Year	65–74	75–84	85+	Total	% change from 2000
2000	3,600	35,000	30,000	68,000	
2010	2,800	30,000	37,000	70,000	3%
2020	3,600	29,000	38,000	70,000	3%
2025	3,900	34,000	38,000	76,000	12%

Source: 2013 Alzheimer’s Disease Facts and Figures-CT specific data

Studies indicate that people age 65 and older survive an average of four to eight years after a diagnosis of Alzheimer’s disease, yet some live as long as 20 years with Alzheimer’s. On average, a person with Alzheimer’s disease will spend more years (40 percent of the total number of years with

Alzheimer’s) in the most severe stage of the disease than in any other stage. It is likely that much of this time will be spent in a nursing home, as nursing home admission by age 80 is expected for 75 percent of people with Alzheimer’s compared with only 4 percent of the general population.

As the population of the United States and Connecticut ages, Alzheimer’s is becoming a more common cause of death. While deaths from other major causes have decreased, deaths from Alzheimer’s disease have increased significantly. Between 2000 and 2010, deaths attributed to Alzheimer’s disease increased by 68 percent, while those attributed to the number one cause of death, heart disease, decreased 16 percent.



Source: 2013 Alzheimer’s Disease Facts and Figures

### Race and Ethnicity and Special Populations-Development Disabilities

While most people in the United States living with Alzheimer’s and other dementias are non-Hispanic whites, older African-Americans and Hispanics are proportionately more likely than older whites to have Alzheimer’s disease and other dementias. Data indicates that in the United States, older African-Americans are about twice as likely to have Alzheimer’s and other dementias as older whites, and Hispanics are about one and one-half times as likely to have Alzheimer’s and other dementias as older whites.

Alzheimer’s disease occurs three to five times more often among people with Down Syndrome than the general population, and often develops at a much younger age (40’s or 50’s) than for other adults.<sup>1</sup> Individuals with Down syndrome and dementia require providers that are knowledgeable about developing plans of care with necessary adaptations for individuals with Down syndrome.

<sup>1</sup> [www.alzheimers.gov/down\\_syndrome.html](http://www.alzheimers.gov/down_syndrome.html)

## Affordability of Long Term Care Services

Few individuals with Alzheimer’s disease and other dementias have sufficient long-term care insurance or can afford to pay out-of-pocket for long-term care services as long as the services are needed. One of the biggest challenges for people living with Alzheimer’s disease and their caregivers is the financial burden of care. This includes the costs of treatments, doctor visits, custodial care services, respite services and institutional care. Every stage of the disease has costs associated with it that can become difficult to manage over time. People living with Alzheimer’s disease often rely heavily on government programs such as Medicare and Medicaid to mitigate these costs. Unfortunately, too often Medicare and Medicaid are inadequate, and the overwhelming costs of this disease exceed available personal funds, leaving families affected by Alzheimer’s in the difficult position struggling to balance care for their loved ones without impoverishing themselves.

AVERAGE ANNUAL PER-PERSON PAYMENTS FOR HEALTH CARE AND LONG-TERM CARE SERVICES, MEDICARE BENEFICIARIES AGE 65 AND OLDER, WITH AND WITHOUT ALZHEIMER’S DISEASE AND OTHER DEMENTIAS AND BY PLACE OF RESIDENCE, IN 2012 DOLLARS				
Payment Source	Beneficiaries with Alzheimer’s Disease and Other Dementias by Place of Residence			Beneficiaries without Alzheimer’s Disease and Other Dementias
	Overall	Community-Dwelling	Residential Facility	
Medicare	\$20,638	\$18,380	\$23,792	\$7,832
Medicaid	10,538	232	24,942	549
Uncompensated	284	408	112	320
HMO	1,036	1,607	236	1,510
Private insurance	2,355	2,588	2,029	1,584
Other payer	943	171	2,029	149
Out-of-pocket	9,754	3,297	18,780	2,378
<b>Total*</b>	<b>45,657</b>	<b>26,869</b>	<b>71,917</b>	<b>14,452</b>

\*Payments from sources do not equal total payments exactly due to the effect of population weighting. Payments for all beneficiaries with Alzheimer’s disease and other dementias include payments for community-dwelling and facility-dwelling beneficiaries.  
Created from unpublished data from the Medicare Current Beneficiary Survey for 2008.

Many people with dementia receive paid services at home, adult day centers, assisted living facilities or nursing homes, or in more than one of these settings at different times in the often long course of their illness. Given the high average costs of these services (adult day services, \$70 per day; assisted living, \$42,600 per year; and nursing home care, over \$142,000 per year) individuals are forced to rapidly spend down their income and assets and eventually qualify for Medicaid.<sup>2</sup>

Medicaid is the only public program that covers the long nursing home stays that most people with dementia require in the late stages of their illnesses.

The prolonged duration of Alzheimer’s (people age 65 and older survive an average of four to eight years after a diagnosis, yet some live as long as twenty years) places increasingly intense physical,

<sup>2</sup> In 2013, a nursing home resident pays on average \$390 a day in Connecticut for a semi-private nursing home bed or over \$142,000 for the entire year. (State of Connecticut Annual Nursing Facility Census, Office of Policy and Management, Policy Development and Planning Division, 2013)

emotional and financial demands on the millions of family members and friends who provide care. Over time, many families become too overwhelmed with the physical and emotional requirements of providing care and are forced to seek the type of round-the-clock care that only can be found in institutional facilities. These families learn that costs for these types of facilities can quickly deplete financial resources. Medicaid is the only federal/state program that covers long nursing home stays, but beneficiaries must be financially and medically eligible to receive coverage. It is a challenge to find quality affordable institutional care that adequately meets the needs of individuals with Alzheimer's.

As Alzheimer's disease progresses to late stages and end-of-life care is needed, many individuals turn to hospice care. Hospice is a covered Medicare benefit that provides comfort, care and support services for people with terminal illnesses in their home or in an institutional facility.

Government programs, such as Medicaid or Veterans benefits provide additional avenues of financial assistance. The strict guidelines for Medicaid require individuals and their spouses to "spend down" most of their assets in order to qualify for assistance thereby risking impoverishing themselves or their spouse.

Many services to support in-home care require paying a large portion of it out-of-pocket. Most of the community-care provided to individuals with dementia are not covered by Medicare. Medicare only covers acute care needs if a patient is "homebound". Most of the needs of people with dementia are chronic care needs and until later stages, may not be homebound.

Private health and long-term care insurance policies funded only about 7 percent of total long-term care spending in 2009. The private long-term care insurance market has decreased substantially since 2010, with major insurance carriers either exiting the market or substantially increasing premiums, making policies unaffordable for many individuals.

### **Health Care Costs to Government**

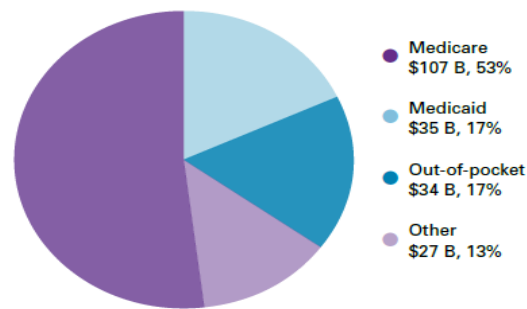
As the number of people with Alzheimer's disease and other dementias grows, spending for their care will increase.

- Older people with the disease have more hospital stays, skilled nursing facility stays and home health care visits than other older people.
- People with Alzheimer's disease and other dementias have more than three times as many hospital stays per year than other older people.
- Total per-person payments from all sources for health care and long-term care for Medicare beneficiaries with Alzheimer's and other dementias were three times as great as payments for other Medicare beneficiaries in the same age group.
- Average Medicaid payments per person for Medicare beneficiaries age 65 and older with Alzheimer's disease and other dementias were 19 times as great as average Medicaid payments for Medicare beneficiaries without Alzheimer's disease and other dementias.

- People with Alzheimer’s and other dementias make up a large proportion of all elderly people who receive nonmedical home care, adult day services and nursing home care.
- About half of all Medicaid beneficiaries with Alzheimer’s disease and other dementias are nursing home residents and the rest live in the community.
- Among nursing home residents with Alzheimer’s disease and other dementias, 51% rely on Medicaid to help pay for their nursing home care.

AGGREGATE COSTS OF CARE BY PAYER FOR AMERICANS AGE 65 AND OLDER WITH ALZHEIMER’S DISEASE AND OTHER DEMENTIAS, 2013\*

Total cost: \$203 Billion (B)



\*Data are in 2013 dollars.

Created from data from the application of The Lewin Model<sup>19</sup> to data from the Medicare Current Beneficiary Survey for 2008. “Other” payment sources include private insurance, health maintenance organizations, other managed care organizations and uncompensated care.

## Caregivers

An estimated 60 to 70 percent of older adults with Alzheimer’s disease and other dementias live in the community compared with 98 percent of older adults without Alzheimer’s disease and other dementias. Of those with dementia who live in the community, 75 percent live with someone and the remaining 25 percent live alone.

Connecticut’s caregivers form an integral and frequently unrecognized part of the health care team; 175,000 family and friends provide an estimated \$2.4 billion in unpaid care to individuals living with Alzheimer’s and other dementias. Of those receiving care, 64.7% are women and 56% of those suffering from Alzheimer’s and other dementias are 85 or older.<sup>3</sup> These informal caregivers may be a family member, friend, or neighbor. There are both positive and negative health outcomes and experiences associated with caregiving. The person providing care, or caregiver, may experience improved well-being when caring for another. However, he or she may also neglect her own health or experience added physical, emotional and financial strain as a result of caregiving duties.

<sup>3</sup> Data come from 2013 Alzheimer’s Disease Facts and Figures and the Behavioral Risk Factor Surveillance System (BRFSS) Caregiver Module administered in Connecticut in 2010. The BRFSS is a public health survey conducted each year by all states, coordinated by the Centers for Disease Control and Prevention (CDC).

Research suggests that caregivers of persons with Alzheimer’s spend more hours providing care than other types of caregivers and provide more intense care- like assistance with eating, bathing, dressing, or other activities of daily living (ADLs) than caregivers of persons without Alzheimer’s disease or dementia. Also, caregivers for people with a cognitive impairment tend to be older than other caregivers, and potentially have more disabilities.

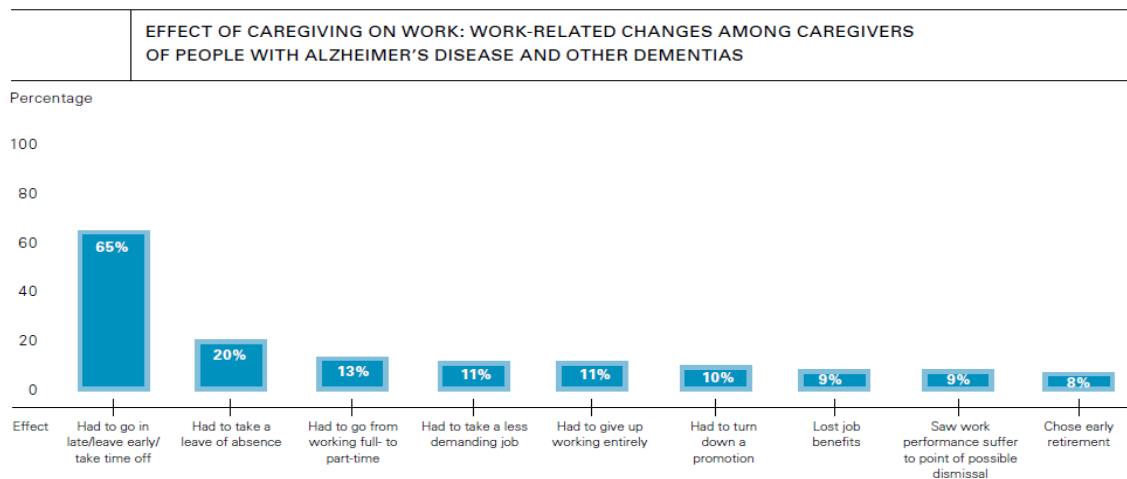
Caregivers of persons with Alzheimer’s disease or dementia provide care for a significantly longer period than caregivers of persons without Alzheimer’s disease or dementia. The self-care activities indicate caregivers of person with the disease may be providing more intense care than other caregivers. They also report that caregiving created or aggravated their own health problems.

//////  
**NUMBER OF ALZHEIMER’S AND  
 DEMENTIA CAREGIVERS, HOURS OF UNPAID  
 CARE, AND COSTS OF CAREGIVING**

Year	Number of Caregivers (in thousands)	Total Hours of Unpaid Care (in millions)	Total Value of Unpaid Care (in millions)	Higher Health Costs of Caregivers (in millions)
2010	170	193	\$2,307	N/A
2011	174	198	\$2,402	\$125
2012	175	200	\$2,461	\$132

Source: 2013 Alzheimer’s Disease Facts and Figures, Connecticut specific data

American businesses incur high costs due to lost productivity, missed work and replacement expenses for employees who are caring for a person with Alzheimer’s or other dementia and have to reduce their hours, take time off or completely quit working.



Created from data from the Alzheimer’s Association.

While relatives, friends and other unpaid caregivers provide significant long-term services and supports, 13 percent of people needing any type of long-term services and supports use paid



assistance in either a primary or secondary role. <sup>4</sup> Due to the aging of the population and the rebalancing towards home and community-based services, demand for paid caregivers is projected to increase. The demand for personal care aides and home health aides is projected to increase substantially.

### Connecticut 2010 and Projected 2020 Occupations

Occupational Title	Employment		Change	
	2010	2020	Number	Percent
Personal Care Aides	15,794	24,162	8,368	53.0%
Home Health Aides	10,533	14,343	3,810	36.2%
Registered Nurses	37,404	44,550	7,146	19.1%
Nursing Aides, Orderlies, and Attendants	23,304	25,848	2,544	10.9%
Occupational Therapists	1,967	2,342	375	19.1%
Occupational Therapy Assistants	616	813	197	32.0%
Occupational Therapy Aids	60	70	10	16.7%
Physical Therapists	3,478	4,538	790	21.1%
Physical Therapist Aides	555	703	148	26.7%
Physical Therapist Assistants	436	562	126	28.9%
Respiratory Therapists	1,360	1,678	318	23.4%
Speech Language Pathologists	1,736	1,999	263	15.1%

Source: Connecticut Department of Labor, Office of Research  
<http://www1.ctdol.state.ct.us/lmi/projections.asp>

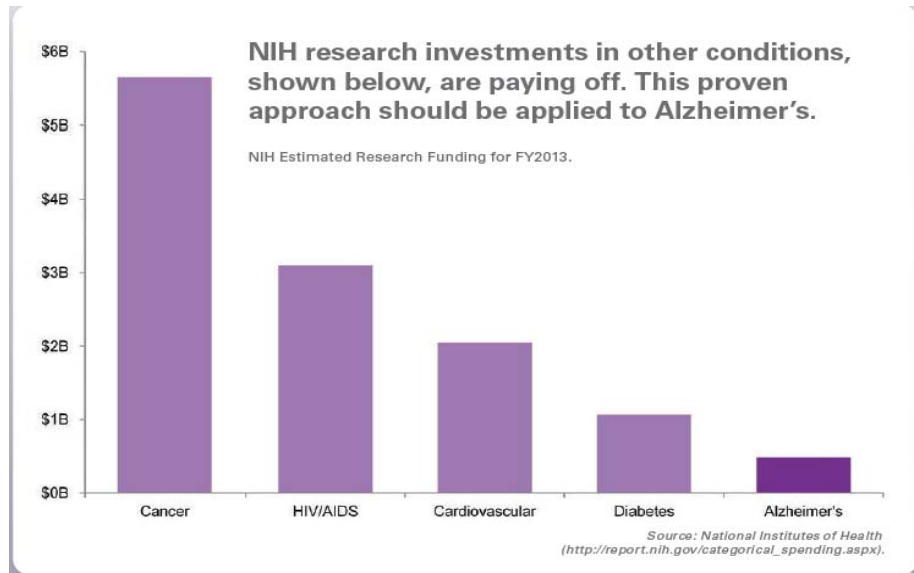
As the number of individuals with Alzheimer’s in the United States is expected to increase substantially over the next few decades, the long-term care workforce will need to expand to meet their needs.

### Research

More than 100 years have passed since German physician Dr. Alois Alzheimer first discovered the amyloid plaques and neurofibrillary tangles in the brain that characterizes Alzheimer’s disease. However, only in the last 30 years has research into the causes, treatments, symptoms and risk factors of Alzheimer’s gained momentum. The only way to find a cure is through research. The majority of research is conducted on the federal level and funded by the National Institutes of Health. Alzheimer’s is underfunded in comparison with other chronic diseases.

---

<sup>4</sup> H. Stephen Kay, Charleene Harrington, and Mitchell P. LaPlante; *Long-Term Care: Who Gets It, Who Provides It, Who Pays, and How Much?*; Health Affairs, Vol.29:1; January 2010; page 15.



To find treatments to stop, slow or even prevent the disease, volunteers for clinical trials are necessary, and investing a significant increase in federal research funding will be needed.

## Findings and Recommendations

### **I. Increase Public Awareness of Alzheimer's and Related Dementias**

Despite the growing number of individuals affected by Alzheimer's disease, there are widespread misconceptions of the disease. Alzheimer's is misperceived as a "normal part of aging." Lack of public awareness leads to insufficient resources dedicated to interventions to address Alzheimer's and under-diagnosis of the disease.

Misconceptions and biases surrounding Alzheimer's can also keep many from seeking a diagnosis or sharing a diagnosis and compound the isolation and depression that often accompanies the disease. A diagnosis of Alzheimer's is most commonly made by an individual's primary physician. However, as many as half of those who meet the diagnostic criteria for dementia have not received that diagnosis from a physician.<sup>5</sup> Several of the barriers to a diagnosis include:

- The time limitations of a routine physician's visit, which make a complete diagnostic evaluation of possible dementia difficult.
- The reimbursement for these visits often limits the time available.
- Physicians may not obtain enough input from the patient's family.
- Physicians may not be well trained in the diagnosis of Alzheimer's Disease and other causes of dementia.
- It may be difficult to find a clinician who is appropriately trained to diagnosis Alzheimer's Disease and other dementias.
- Physicians may feel that the diagnosis is of limited value because of the absence of disease-modifying treatments.
- The diagnosis of younger-onset dementia may be delayed because symptoms may be attributed to other conditions.
- Clinicians may not have a full understanding of the cultural differences of diverse and special populations.

Benefits of early detection may include improved quality of life and more time to plan for the future, increased chances of participating in clinical drug trials, an opportunity to participate in decisions about care, transportation, living options, financial and legal matters, and care and support services - making it easier for self and family to manage the disease. In addition, families and physicians will recognize the need for increased medical supervision, and the individual's increased risk for complications of medications, hospitalizations and surgery.

Those who receive a diagnosis are left with questions on what to expect and where to get help. People are left to piece together information and support from a patchwork of agencies and coordinate care among multiple providers and identify appropriate long-term supports in a complicated health care system. Individuals and caregivers need timely information about available

---

<sup>5</sup> Boustani, Peterson, Hanson, Harris & Lohr, 2003; Bradford, Kunik, Schultz, Williams & Singh, 2009

services, resources and supports that will assist them in preparing not only for current needs, but future needs based on the disease progression.

## Recommendations

### **Public Education and Outreach**

- Create a public/community awareness campaign through partnerships, including, but not limited to, the Alzheimer’s Association, AARP, State Department on Aging, Area Agencies on Aging, faith-based and immigrant communities, business/corporate associations, chambers of commerce, medical community and professional/trade associations to increase community and family awareness of resources, including the Alzheimer’s Association Help Line and 211.
  - Develop a media campaign to bring awareness of dementia resources to the public including, but not limited to, media messages on buses, distribution of information at libraries, senior centers, pharmacies, etc. to increase visibility.
  - Create public service announcements that raise awareness of the importance of timely reporting of missing individuals with Alzheimer’s disease or related dementias. Increase awareness of the Silver Alert system and the Safe Return program.<sup>6</sup>
  - Raise public awareness about the disproportional impact of Alzheimer’s disease and dementia on minority populations and the likely development of dementia in individuals with Down syndrome.
- Disseminate informational packets to be distributed at doctors’ offices, pharmacies, senior centers and other locations for individuals diagnosed with Alzheimer’s disease and caregivers. Much of this information is available through the Alzheimer’s Association.
- Each municipality shall designate a town official or employee to serve as a dementia care designee. Such designee shall be trained in dementia core competencies. **(Requires legislation)**

### **Early Detection**

- Increase awareness to healthcare providers about validated cognitive assessment tools that could be administered in the continuum of settings, such as physicians’ offices, clinics, emergency rooms, and acute care hospitals.
- Promote Medicare Annual Wellness visits which includes a cognitive impairment assessment for early detection and diagnosis, but is often not conducted in the visit.

---

<sup>6</sup> When any person over the age of 65, any person over the age of 18 with a mental impairment, or any person under age 18 is reported missing, a silver alert is issued through the Missing Person Clearinghouse which is a function of the Department of Emergency Services and Public Protection.

- An individual’s medical record is the primary documentation for all medical history, co-morbidities, therapies and outcomes. It informs care recommendations and next steps toward comprehensive care for the overall health of the patient and caregiver. Encourage practitioners to thoroughly document any cognitive changes in an individual’s medical record.
- Compensate providers for the time required to collect and analyze the data for a thorough clinical assessment.

### ***Abuse, Neglect and Exploitation***

Cognitive impairment poses the most significant risk for exploitation. Studies have shown as many as 1 in 10 older adults are victims of elder abuse and this number increases to 1 in 2 for those with dementia. Elder abuse occurs in both homes and facilities and manifests in many forms including financial, sexual, physical and psychological abuse as well as neglect and self-neglect.

- Collaborate with elder abuse prevention entities at the state and local level to ensure awareness of risks to individuals with dementia and how to protect them from abuse.
- Develop a bank reporting project that includes bank reporting training programs. Bank personnel may be in a unique position to detect financial exploitation of older adults and individuals with dementia. Employees should be trained about potential red flags that indicate suspicious activity. Potential red flags include: Recent changes to a person's will, misuse of Power of Attorneys, unusually high levels of activity or out-of-state charges. Banks should have immunity after reporting and addressing suspicious activity. (This recommendation supports a similar recommendation of the Aging in Place Task Force) **(May require legislation)**
- Enhance efforts to prevent exploitation of individuals with dementia by supporting initiatives such as the State Department on Aging’s “Elder Justice Coalition”. **(Potential fiscal impact)**

### ***Advanced Planning***

- To minimize family disputes, ensure that the wishes of the individual are known and respected, and avoid costly court proceedings, encourage financial planning (including assessment of assets) and advanced directives with the help of an attorney with specific knowledge in elder, probate or estate law.
- Encourage financial institutions to provide information about financial planning tools for individuals with dementia.
- Recognizing that individuals with debilitating conditions may not be able to fund their child’s college education due to their significant medical and long-term care expenses, we recommend the criteria for federal financial aid for college be reviewed to determine if parents’ medical expenses are taken into account when determining the level of financial aid

the applicant is eligible for. If medical expenses are not taken into account, we recommend a letter be sent to Connecticut’s Congressional delegation encouraging them to pursue a change to the federal financial aid criteria to recognize parents’ medical expenses. **(Federal)**

- Amend the state tax code to include a Dependent Care Credit where the tax filer can receive a credit for care expenses incurred so the caregiver is able to work. Home care and adult day care costs are examples of work-related expenses that may be eligible. **(Requires legislation - fiscal impact)**
- Amend the state tax code to provide a deduction or credit for tax filers for the premiums paid for a private long-term care insurance policy. **(Requires legislation-fiscal impact)**
- Encourage the Connecticut Congressional delegation to work towards passage of a federal “above-the-line” tax deduction for the premiums paid for a private long-term care insurance policy. **(Federal)**
- Provide tax incentives to corporations which offer affordable on-site Adult Day Care services for families of employees. **(Requires legislation – fiscal impact)**

## II. Enhance Services and Supports for Individuals with Alzheimer’s and Related Dementias and Their Family Caregivers

Alzheimer’s disease is a condition needing special focus due to the high need for health and long-term care services by individuals with Alzheimer’s and their caregivers. Research shows that older people with Alzheimer’s or other dementias have twice as many transitions between hospital, home, and nursing home as other older people. There is a need to improve care practices and all types of care transitions for people with these conditions, including transitions to and from assisted living, nursing home, rehabilitation facility, emergency department, hospital, and home.<sup>7</sup>

Case management and effective care coordination has the potential to significantly reduce the number of people needing expensive skilled nursing homes. Many of the services are unknown or are discovered by families too late. Improved coordination can assure smoother transitions of care and avoid confusion navigating health care, housing and social services. Some programs are in place to assist Alzheimer’s individuals and their families (Appendix C).

Opportunities exist to transform health care by improving coordination between medical care, long-term care and community components. Several demonstration projects in Connecticut through the Affordable Care Act are underway such as the Balancing Incentive Program, Medicare and Medicaid Enrollee Integrated Care Demonstration and State Innovation Model.

---

<sup>7</sup> Callahan, C.M., Arling, G., Tu, W., Rosenman, M.B., Counsell, S.R., Stump, T.E., and Hendrie, H.C. (2012) “Transitions in care for older adults with and without dementia.” *Journal of the American Geriatrics Society* 60 (5):813-820.

## **Informal Caregivers**

Once a diagnosis of Alzheimer's is made and disclosed, as few as half of patients and families receive counseling, support, or information about next steps. This information is important, especially for early stage patients who experience positive outcomes when they are involved in planning and receive appropriate services.<sup>8</sup> Furthermore, relatives, friends and unpaid caregivers currently provide the majority of long term supports and services in the home. Caregiving for an individual with Alzheimer's or related dementia is challenging, and caregivers often do not have adequate support or training in the medical and personal care tasks they need to perform. Greater caregiver knowledge of dementia management is associated with higher quality care. The role and responsibility of being a caregiver is associated with significant mental and physical health risks. Therefore, there is a need to educate caregivers to recognize changes in the disease and adjust expectations accordingly.

## **Recommendations**

### **Programs and Services**

- Support and enhance rebalancing initiatives that focus on diversion of individuals with dementia who are at risk of nursing home placement to community-based settings.
  - Increase funding to expand the CT Statewide Respite Care Program to reflect the growing demand. **(Fiscal impact)**
  - Expand and set aside slots for individuals with younger onset Alzheimer's disease in the Connecticut Home Care Program for the Disabled. **(Requires legislation, fiscal impact)**
  - Adult Day Care represents an option that prevents isolation and can delay or completely divert individuals from nursing facilities. Due to limited and diminishing reimbursements, several of Connecticut's Adult Day Centers are reducing services or closing. Ensure Adult Day Centers remain a viable community care option by increasing the current reimbursement level to meet operating costs based on level of care provided (e.g. medical model requires nurses, aides and medication/health monitoring). The daily rate should include transportation costs. Reimbursements should be adjusted annually to reflect Cost of Living Adjustments. **(fiscal impact)**
- Explore federal funding for research and demonstrations. The 2010 Affordable Care Act is providing funding for time-limited innovation and demonstration projects that could result in new information about the cost-effectiveness of Alzheimer's and dementia treatments and care practices centered around care coordination and transitional care models. Support CT's existing initiatives such as the State Innovation Model (SIM) and Medicare and Medicaid Enrollees Integrated Care Demonstration and encourage focused efforts on individuals with dementia.

---

<sup>8</sup> Chosdosh, J, Mittman BS, Connor KI. Caring for patients with dementia: How good is the quality of care? Results from three health systems. *J Am Geriatr Soc.* 2007; 55(8): 1260-1268.

- Facilitate outreach and public/private collaborations to individuals with Down syndrome and dementia, high risk minority populations and people with younger onset dementia.
- In order to alleviate isolation and enhance safety of individuals with dementia, support and strengthen programs that provide consistent contact and outreach such as, a reverse 911 system or the implementation of a telephone reassurance program, like the the “R U OK” program. **(Fiscal impact)**
- Encourage and incentivize employers to offer and promote employees to carry long-term disability insurance.

### ***Transportation and Driver Safety***

At some point the ability to drive safely poses a unique challenge for an individual with dementia. The individual may not possess the insight to know they are unable to drive. In addition to significant risks to public safety, this poses three distinct issues: 1) effective assessments for driving ability; 2) need for reassessment of driving ability; and, 3) transportation to maintain independence. Current driving assessments may not include visual processing speed, judgment for spatial orientation and planning, nor challenge problem solving in difficult driving conditions. Families often find themselves in the position of having to “take away the keys” and prohibiting driving of an impaired person with dementia. Current options for families are to ask the doctor to complete a medical affidavit preventing driving, request for the Department of Motor Vehicles (DMV) to review, and law enforcement revocation of license.

- The DMV shall explore policies and regulations related to revoking drivers’ licenses. Encourage the legislature’s Transportation Committee and DMV to consider cognitive impairment evaluations. **(State departmental programmatic policy)**
- Department of Motor Vehicles shall take a proactive approach to educating physicians about reporting unsafe drivers to the DMV.
- Identify and implement use of driving assessments which measure cognitive ability or cognitive impairment. Encourage driver assessment programs at all hospital and diagnostic assessment units, major rehabilitation centers (especially those which offer Occupational Therapy).
- When a driver’s license is revoked, the individual shall be referred to social and community agencies for assistance with transportation needs.
- Promote use of Municipal Grants money for transportation support of people diagnosed with cognitive impairment. Unused money in Municipal Grants shall be distributed for use for disabilities transportation annually to those municipalities which were awarded grants for transportation services that year. **(Requires legislation)**



- Expand Dial-a-Ride and ADA transportation services, and include escorted door-to-door services for people with dementia. **(Requires legislation-fiscal impact)**
- Expand transportation services to promote socialization, fitness/wellness, education, connection to community centers, volunteer/civic engagement, etc.

### **Provider Services**

- Study the financial impact of developing a Dementia Centers for Excellence (COE) or geriatric assessment units (GAU) at CT hospitals.
- Incentivize hospitals to develop regional geriatric assessment units (GAU) and dementia centers for excellence (COE). The GAU/COE would include medical screening, psychiatric screening and service, counseling and educational opportunities.
- Incentivize clinics that collaborate with academic centers, like University of Connecticut and Yale University, to offer National Institutes of Health (NIH) sponsored clinical trials throughout the state of Connecticut.
- In order to support consumers and caregivers, standardize the immediate provider response following an Alzheimer's/Dementia diagnosis to include:
  - Unless clinically contraindicated, clinicians should inform individuals of their diagnosis.
  - Referral to the Alzheimer's Association Helpline for immediate triage of needs and resources nationally and throughout the state: 1-800-272-3900.
  - Immediately begin assisting the individual to identify a support person and invite them to the next follow-up visit (adhering to HIPAA requirements).
  - All individuals should be educated about clinical trials and given the option to participate.
- Ensure coordination and connection to support services including:
  - A provision of simple organized information, a checklist of necessary steps, referrals to the Alzheimer's Association, Area Agencies on Aging, other community organizations for guidance with accessing services and support.
  - The identification of a care coordinator to counsel a newly affected family through the care process. A care coordinator can assess individual and caregiver needs; develop a care plan; assist in navigating and accessing services.
  - Support using models of integrated care to connect social workers, counselors, and lawyers under a comprehensive unified dementia support system to reduce pressure for families dealing with a fragmented, confusing patchwork of services and supports.
  - Charge an agency to review all current statewide dementia resources and ensure that the resource remain organized and easily accessible.
- Support development of adequate assessment tools, community based services and supports and program eligibility for individuals with Down syndrome and dementia, high risk

minority populations and people with younger onset dementia. Encourage promotion and public awareness of centers which offer evaluation, treatment and support for these special populations.

### III. Improve the Quality of Care for Individuals with Alzheimer’s and Their Families

There are few generally recognized and accepted quality standards to measure dementia care that physicians, nurses and other health care professionals provide to Alzheimer’s patients across long-term care and hospital settings. Connecticut will also need to increase the number of health care professionals and ensure they are competent to serve individuals with Alzheimer’s and related dementias. Studies indicate that 68% of residents of skilled nursing facilities have some degree of cognitive impairment. Twenty-seven percent have very mild to mild cognitive impairment, and 41 percent have moderate to severe cognitive impairment.<sup>9</sup> Because of the comprehensive impact dementia has on long-term care residents, there needs to be a dedicated level of commitment to meeting the needs of persons with dementia, while focusing on remaining abilities and quality of life indicators.

#### Recommendations:

- Charge a group of medical providers to review specific strategies to best integrate Dementia Care best practice guidelines, including quality care protocols, into clinical practice. The Alzheimer’s Association has established practice guidelines that can be referenced.
  - Provide financial incentives to providers who use established best practices.
- Dementia quality care standards shall include a review of staffing patterns, mandating consistent care assignments and understanding of the life history of the resident.
- The Department of Social Services developed the Interagency Referral Form (W10) to serve as physicians’ orders for diagnoses, medications, treatments, recent immunizations, and allergies, as well as demographic information. The one-page form or an electronic version of the form developed by the facility is used by hospitals, nursing facilities and home care agencies to communicate essential care information for patient well-being. The Departments of Social Services and Public Health shall update the Interagency Referral Form (W10) to include a person-centered dementia care profile for pain management, wandering history, safety issues and behavioral triggers and reactions, or reflect other dementia care vulnerabilities and history. The form shall be used across the continuum of care providers.  
**(May require legislation)**
- Review, and revise as necessary, the Department of Public Health’s Assisted Living Services Agency (ALSA) regulations to reflect the increasing level of functional needs of individuals

---

<sup>9</sup> US Department of Health and Human Services, Centers for Medicare and Medicaid Services. Nursing Home Data Compendium; 2010 Edition

living in Managed Residential Communities (MRC is Connecticut's term for Assisted Living Facilities) and the increasing number of MRC residents with some level of cognitive impairment. **(May require regulatory changes)**

- Many new models of care (e.g. Green House Model and small home models) require substantial waivers because the Connecticut Public Health Code needs updating. *“The State needs a collaborative, flexible and efficient regulatory environment that is adaptive and receptive to individual provider’s forward thinking ideas and planning. Such an environment would encourage providers of the long-term services and supports continuum to adjust, modernize and diversify their models of care to address current and future consumer needs and expectations, which in turn should lead to higher quality care.”* (2013 Long-Term Services and Supports Plan). The Public Health Code shall be updated to achieve this stated goal. **(State departmental policy/regulations, may require legislation)**
- The Department of Public Health shall create a new affordable licensure model for Homemaker and Companion Agencies. The licensure shall include requirements that employees receive dementia training. Employees will not be required to be licensed. **(Requires legislation, potential fiscal impact)**
- Develop an independent care manager registry through the Department of Consumer Protection. (Requires legislation, potential fiscal impact)
  - Geriatric Care Managers or companies who offer case management services must have dementia core competency training.
  - Agencies or organizations which provide care management must develop benchmark and monitor quality indicators.
- Improve continuing education efforts to healthcare providers to recognize signs of dementia and the importance of counseling to individuals and their care partners.
- Strengthen community education about the importance of oral health in older adults, and address provider payment and shortage issues in dental care. Expand coverage and benefits to include comprehensive dental care as an “essential health benefit” under the Affordable Care Act, Medicare, Medicaid, and private insurance options. (Federal)
- Emerging research and technology may soon make diagnosis of Alzheimer’s and other related dementias possible at a pre-clinical or pre-symptomatic stage. For example, before someone develops a cognitive impairment, medical tests could determine that a person has the disease bio-markers. Review laws and regulations to ensure the rights of persons with Alzheimer’s or other dementias and diseases are protected.

## **Workforce Education and Training**

### **Ensuring an Adequate Workforce**

The professional workforce specifically trained to meet the long term care services and support needs of the older adult population will not be adequate to meet the future needs for long term care supports and services. (See Connecticut's Projected Occupations Table on Page 17)

There were only 7,356 board-certified geriatricians in the United States in 2012, and there is only about 1 geriatric psychiatrist for every 11,000 adults. If current rates continue, there will only be 1 for every 20,000 older persons by 2030. In addition, nurses who provide a significant amount of care for older adults have high rates of turnover in nursing homes.<sup>10</sup>

The anticipated increase in the demand for direct care workers could lead to a shortage of experienced workers. Difficulty in attracting and retaining qualified workers may affect the quality of care that individuals receive.

### **Ensuring an Educated Workforce in Dementia Care**

There are few Alzheimer's and dementia care training requirements for health care professionals and facilities serving individuals with Alzheimer's disease or dementia in Connecticut. It is estimated that sixty eight percent of nursing home residents in Connecticut have some form of dementia. Yet, Connecticut only requires Alzheimer's special care units or programs to provide dementia-specific training. (See CGS Sections 19a-562 and 19a-562a)

Individuals with Alzheimer's or other dementias are served throughout the health care system and community. Many health care professionals and others are not equipped to deal with the unique needs of individuals with Alzheimer's or related dementias.

Enhanced specialist training is needed to prepare the direct care workforce for the unique challenges faced by people with Alzheimer's disease. Dementia specific capabilities need to be expanded and enhanced to ensure a dementia competent workforce with the skills to provide high quality care.

Connecticut's aging population and re-balancing initiatives toward home and community-based services will increase demand for direct care workers employed in community-based settings, such as home health aides, homemakers and companions and personal care assistants. Seventy percent of individuals with Alzheimer's or related dementias reside in the community, and this is likely to increase the demand for home care services and supports. Currently, there are no dementia specific training requirements for home and community-based providers.

---

<sup>10</sup> Commission on Long-Term Care, Report to Congress, September 2013.

### **Increase Public Safety for Individuals with Alzheimer's Disease**

When an individual with Alzheimer's disease has gone missing or is in a difficult situation, it is often a first responder's job to diffuse the situation and provide protective services. Police and fire departments, emergency medical technicians and hospital emergency departments interface with individuals with Alzheimer's, but are not educated about medical and behavior issues when responding to an emergency involving these individuals and their families.

### **Recommendations**

- Revise CGS § 19a-522c to require a Dementia Care Committee in each facility to review the issues which impact person-centered care, wellness indicators, and staff training programs for dementia care capability. Each facility will designate one staff person who will monitor the day to day implementation of the issues directed by the Dementia Care Committee. The dementia care designee will meet educational competencies and participate in regular continuing education in dementia certification programs.
- Revise CGS § 19a-522c to require all staff to receive dementia-specific education upon hire and annually thereafter. This education and training shall be provided by a subject matter expert or a person who has received dementia training from an accredited body of knowledge such as (but not limited to) the Alzheimer's Association or the National Council of Dementia Practitioners through a "Train the Trainer" program. This individual must meet the annual requirements for re-certification as stated in the training program.
- Revise CGS § 19a-562a to require that dementia-specific training shall be completed within 120 days of hire. (Currently training is required within 6 months of hire). This education and training shall be provided by a subject matter expert or a person who has received dementia training from an accredited body of knowledge such as (but not limited to) the Alzheimer's Association or the National Council of Dementia Practitioners through a "Train the Trainer" program. This individual must meet the annual requirements for re-certification as stated in the training program.
- Require residential care homes, assisted living facilities, adult congregate living facilities, adult day care centers, hospice, home health agencies and homemaker/companion agencies to provide dementia –specific education to staff upon hire and annually thereafter.
- Amend educational and licensure regulations for nursing home administrators to include a course in dementia (CGS § 19a-519).
- Currently, regulations for dementia training exist in Alzheimer's special care units or programs. There is a need to educate large numbers of people in fields and in roles that connect with individuals with dementia. Create a system of "tiered" education to meet the workforce needs. These levels of education should correlate to the level and degree of connection that the caregiver has to the person with dementia. (see Appendix B for a list of identified groups in need of this education)

- Encourage utilization of resources and standardized dementia trainings for the home and community based direct care workforce, family members, and unpaid caregivers so they have access to affordable and impactful educational opportunities and to ensure minimum level of competency in dementia.
  - Develop an affordable “train the trainer” dementia course based on the existing Alzheimer’s Association caregiver support group leaders’ training. Develop a model similar to the American Red Cross’ CPR training program, whereby trained educators could then offer accessible and affordable dementia education to caregivers or others in the community.
  
- Increase connectivity and training opportunities for the home and community based direct care workforce by utilizing emerging high tech training and education models.
  
- Collaborate with professional and trade associations to develop an Alzheimer’s disease and related dementia education program using continuing education credits (CEUs and CMEs) for health care professionals, including physicians, nursing, social workers, administrators, care managers (public and private), transition coordinators and pharmacists.
  
- Require mandatory dementia-specific training for hospital emergency room staff, including nurses, physicians and medical technicians. Build upon the existing collaboration between the Alzheimer’s Association- CT Chapter and the CT Hospital Association. **(May require legislation)**
  
- Integrate and continue basic level of dementia training and education for public safety responders, long-term care ombudsman, protective service employees, probate judges and court personnel. Expand annual missing persons police force training to include dementia education (CGS § 7-294o). **(May require legislation)**
  
- Encourage a basic level of dementia education for conservators and other fiduciaries responsible for the care of those no longer capable of managing their person or affairs, such as trustees and powers of attorney.
  
- Encourage Connecticut hospital emergency rooms to have a designated and trained Alzheimer’s disease liaison/specialist to address the acute needs of individuals with dementia as well as act as a resource for police and first responders. Adopt an approach similar to the Sexual Assault Nurses Emergency (SANE) model.
  
- Coordinate a communications system between hospitals and emergency responders in cases of Silver Alerts.
  
- Integrate dementia education in curriculum and residencies at Connecticut’s medical universities.

- Create financial incentives, such as tuition assistance, loan forgiveness, subsidies and stipends to address workforce shortages, including recruitment and retention strategies, through education and training programs to increase the number of health care professionals who pursue education and training to specialize in gerontology and geriatrics.
- Encourage use of and reimbursement for tele-monitoring<sup>11</sup> and other new technologies to aid in monitoring of health status by consumers and others and provide support to caregivers.
- Collect accurate and relevant data on current dementia workforce needs and develop future workforce projection models in order to target the highest need professions.

Sustained involvement of consumers (including adequate representation from special populations), caregivers, providers and private and public entities shall continue in order to implement the recommendations outlined in this report.

---

<sup>11</sup> The definition of tele-monitoring according to the US Department of Health and Human Services is the process of using audio, video, and other telecommunications and electronic information processing technologies to monitor the health status of a patient from a distance.

## Appendix A: Information about Alzheimer's

### 10 Signs of Alzheimer's

Memory loss that disrupts daily life may be a symptom of Alzheimer's, a fatal brain disease that causes a slow decline in memory, thinking and reasoning skills.

There are 10 warning signs and symptoms of Alzheimer's. Every individual may experience one or more of these signs in different degrees. If you notice any of them, please see a doctor.

1. Memory loss that disrupts daily life
2. Challenges in planning or solving problems
3. Difficulty completing familiar tasks at home, at work or during leisure time
4. Confusion with time or place
5. Trouble understanding visual images and spatial relationships
6. New problems with words in speaking or writing
7. Misplacing things and losing the ability to retrace steps
8. Decreased or poor judgment
9. Withdrawal from work or social activities
10. Changes in mood or personality

### 7 Stages of Alzheimer's

Alzheimer's symptoms vary. The stages below provide a general idea of how abilities change during the course of the disease. Not everyone will experience the same symptoms or progress at the same rate.

This seven-stage framework is based on a system developed by Barry Reisberg, M.D., clinical director of the New York University School of Medicine's Silberstein Aging and Dementia Research Center:

1. No impairment (normal function)
2. Very mild cognitive decline (may be normal age-related changes or earliest signs of Alzheimer's disease)
3. Mild cognitive decline (early-stage Alzheimer's can be diagnosed in some, but not all, individuals with these symptoms)
4. Moderate cognitive decline (mild or early-stage Alzheimer's disease)
5. Moderately severe cognitive decline (moderate or mid-stage Alzheimer's disease)
6. Severe cognitive decline (moderately severe or mid-stage Alzheimer's disease)
7. Very severe cognitive decline (severe or late-stage Alzheimer's disease)



## Appendix B: Recommended Tiers for Workforce Education and Development

1. Professional licensed and registered (or certified) direct caregivers across the continuum of care for Hospital, Nursing Facility, Assisted Living, Adult Day Center, Home Care Agency, Group Home or in private practice including, but not be limited to physician, APRN, PA, Registered Nurse, Licensed Practical Nurse, Physical Therapist, Occupational Therapist, Speech Therapist, Case Managers, Certified Nursing Assistants, Dieticians, First Responders – Police, Fire, Emergency Medical Technicians. Include education for these groups at the college/university/certification level
2. Professional licensed and registered (or certified) indirect caregivers across the continuum of care for Hospital, Nursing Facility, Assisted Living, Adult Day Care Home Care Agency, Group Home or in private practice including, but not be limited to, lawyers, protective services, social workers, pharmacists, human resource directors, EAPs, administrators, executive directors, prison and corrections personnel, court officials, protective services, town/regional directors for public health, town/regional directors for agency on aging
3. Unlicensed, unregistered direct caregivers including, but not be limited to, home health aides, homemakers, personal care assistants, companions associated with a Home Health Agency, Group Home or in private practice
4. Unlicensed, unregistered indirect caregivers across the continuum of care for Hospital, Nursing Facility, Assisted Living, Adult Day Center, Home Care Agency, Group Home or in private practice including, but not be limited to, housekeeping, food services, environmental services, clerks/unit managers
5. Community providers/vendors including, but not limited to, Senior Center Director, Housing Authority, Adult Education, bank manager, clergy, CPA, financial planner, librarian, office managers for physicians, dental, podiatry, vision, audiology

## Appendix C: Connecticut Programs and Community Resources

The following list outlines programs and services in Connecticut. ***The list provides an overview of the services and is not exhaustive, and not all programs and services are designed specifically for people with Alzheimer's and related dementias.***

### Information and Support:

- *State Department on Aging* Established on January 1, 2013, the State Department on Aging is responsible for developing programs and providing services for nearly one fifth of Connecticut's population. Approximately 710,000 citizens in the state are over the age of 60, an increase of 18 percent over the last decade. All department programs are designed to improve the quality of life and to help elderly people live with dignity, security and independence.
- *The Department of Social Services (DSS)* services families and individuals that need assistance in maintaining or achieving their full potential for self-direction, self reliance and independent living. DSS provides a continuum of core services for eligible residents of Connecticut to access basic needs services. Within these core services, DSS programs allow for the provision of food, shelter, financial support, health services and increase the support and safety of Connecticut's most vulnerable citizens.
- *Aging and Disability Resource Connection* Connecticut's Aging & Disability Resource Centers are known as "Community Choices." Community Choices is a powerful information hub linking older adults, persons living with disabilities, and caregivers in Connecticut to the services and supports they seek. The staff can connect you to everything from a name and phone number to more detailed information regarding community services through activities such as benefit screening, options counseling, and care transitions.
- *Alzheimer's Association, CT Chapter* provides services to those affected by Alzheimer's and other dementias; advocates for policy change and research funding; and advances research toward prevention, treatment, and a cure. The Alzheimer's Association offers programs and services to help those impacted by Alzheimer's and related dementias such as the toll-free helpline, care consultations, support groups, MedicAlert +Alzheimer's Association Safe Return, Early Stage Programs, Community Education and Professional Training, and Trialmatch.
- *Area Agencies on Aging (AAA)* The state receives significant federal support for elderly programs through the Older Americans Act. Federal funds are allocated to five AAAs, which arranges with local providers for the delivery of services on a regional basis. State funds supplement the federal funds.

## Community Services and Programs

- Home and Community-Based Services Waivers These Medicaid waivers provide non-traditional services, such as case management and homemaker services, to targeted populations as an alternative to institutionalization. The state's home and community-based services waivers serve frail elders, as well as persons with disabilities, acquired brain injury, developmental disabilities and serious mental illness.
- The Center for Medicare Advocacy, Inc., Established in 1986, is a national nonprofit, nonpartisan organization that provides education, advocacy and legal assistance to help older people and people with disabilities obtain fair access to Medicare and necessary health care. The Center is headquartered in Connecticut and Washington, DC with offices throughout the country. The Center is staffed by attorneys, nurses, legal assistants, and information management specialists. The Center's work includes: representing individuals in appeals of Medicare denials, responding to telephone and email inquiries, producing a wide array of electronic and hard copy educational materials, advocating in administrative, judicial, and legislative forums, pursuing Medicare coverage for individuals and for dually eligible beneficiaries (individuals who are eligible for both Medicare and Medicaid) and providing legal training and support nationwide as well as for Connecticut's state health insurance and assistance program (SHIP program), known in Connecticut as CHOICES
- CHOICES is Connecticut's federally recognized state health insurance assistance program, which provides older and disabled adults with health insurance assistance, outreach, information and referral counseling, and eligibility screening.
- Connecticut National Family Caregiver Support Funded under Title III E of the Older Americans Act, this program provides services to caregivers, including family members caring for relatives 60 and older, and grandparents or older relatives caring for children 18 years of age or under. Caregiver training, counseling and support group services are provided to consumers. Respite services are provided to caregivers and supplemental services such as home safety devices, medical supplies and medical-related equipment are provided to consumers.
- CT Statewide Respite Care Program The Statewide Respite Care Program offers respite services, support, and information to families coping with Alzheimer's disease. It provides a temporary break to caregivers from daily caregiving responsibilities and can strengthen a caregiver's ability to continue home care, while improving quality of life for the person with the disease by offering additional supports and enhancing their ability to remain at home. Individuals receive direct services such as adult day care and home health.

- Adult Day Centers These centers provide social activities as well as more intensive health, therapeutic and social services for persons with severe medical problems or who are at risk of nursing home placement.
- CT Home Care Program for Elders The Connecticut Home Care Program for Elders provides home and community-based services to frail elders as an alternative to nursing home placement. The program has a state funded as well as a Medicaid waiver component, serving individuals based on their functional needs and financial eligibility. Approximately 25% of program participants are served under the state-funded component of the program, which requires participants to contribute to the cost of their care equal to 7% of their monthly care plan costs.
- CT Home Care Program for Disabled This program provides home-based services to up to 50 persons between the ages of 18 and 64, who have been diagnosed with a degenerative neurological condition and who are not eligible for other programs but need case management and other supportive services to remain in the community. The program mirrors the state-funded component of the Connecticut Home Care Program for Elders.
- Long term Care Ombudsman Program responds to complaints regarding the quality of care provided to the 37,000 residents living in Connecticut's skilled nursing facilities, residential care homes and assisted living facilities.
- Money Follows the Person (MFP) Rebalancing Demonstration The MFP program makes services available to transition Medicaid eligible clients back to the community who have been residents of nursing homes or other institutions for three months or more. This program works in partnership with the federal government and receives an enhanced federal match. The program, which began operation in December of 2008, has been a leading force in the state's efforts to rebalance the system of long-term services and supports to create a system that better supports consumers' informed choice. In addition to transition services, the demonstration funds initiatives designed to increase options for long-term services and supports in the community as an alternative to institutionalization.
- Connecticut Partnership for Long-Term Care The Partnership is the state of Connecticut's alliance with the private insurance industry providing education and outreach and offering, through private insurers, special long-term care insurance to help individuals increase their options and to avoid impoverishing themselves when paying for their long-term care. The Partnership which is coordinated by the Office of Policy and Management has an information and education program managed by DSS. This education program offers one-on-one counseling, distributes materials, and conducts regional public forums and other presentations.
- Protective Services for the Elderly This program is designed to safeguard people 60 years and older from physical, mental and emotional abuse, neglect and abandonment and/or financial

abuse and exploitation. DSS social workers devise a plan of care aimed at assuring an elder's safety while preserving the person's right of self-determination. Staff may help the person remain in the living situation he or she prefers, safeguard legal rights, prevent bodily injury or harm, determine service needs and then mobilize resources to provide necessary services. The Social Work service plan may include crisis intervention, arranging for and coordinating any of the following services: adult day-care, companionship, counseling, homemaker, home health care, home-delivered meals, long-term care or, if necessary, emergency convalescent placement. In extreme cases, DSS can seek court authorization to provide services to a person who appears to "lack the capacity" to give consent to reasonable and necessary services to assure personal safety. Under certain circumstances, the Department may apply to the Probate Court for the appointment of a Conservator whose role is to make decisions on behalf of an incompetent person.

- Elderly Nutrition Services The state Department on Aging provides funding under Title III C of the Older Americans Act as well as state appropriations to serve nutritionally balanced meals and provide nutrition education to individuals 60 years and older and their spouses at 181 senior community cafes statewide, as well as in the homes of frail, homebound or otherwise isolated older adults. The meals are intended to improve the dietary intakes of participants while offering opportunities for socialization.
- Elderly Health Screening Program This program provides health screening services, geriatric assessments, follow-up care and programs related to health promotion and wellness to persons age 60 and over at various sites throughout Connecticut.
- Hospice Hospice programs provide comfort care and preserve the dignity of those in the late stages of terminal illness while also offering support services to families. It can be provided at home or in a hospital or residential care facility. A hospice team includes a doctor, nurse, social worker, dietician, clergy and trained volunteers. They work together to address the physical, emotional, and spiritual care of the person as well as the family. For Medicare to cover hospice care, a doctor must estimate that the person has six or fewer months to live. Hospice benefit may be extended if the person lives longer than expected.
- The Connecticut Statewide Fall Prevention Initiative strives to decrease the rate of falls among older adults by embedding an evidence-based risk assessment and intervention strategy throughout Connecticut by participating in activities to reduce risk of falls.
- Senior Medicare Patrol This federally funded project ensures that seniors are empowered to prevent, detect, and address issues of health care fraud, errors, abuse and other related health care scams through outreach and education including volunteer presentations, one-on-one counseling and assistance.

- Statewide Legal Services provides free legal advice and referrals to Connecticut’s legal aid programs for very low-income people living in Connecticut who can't afford a lawyer. • ost of SLS’s legal services are available only for people with income at or below 125% of the federal poverty level. If 60 years old or older and income is higher than this, the legal aid office can be contacted. SLS only provides free legal assistance in some kinds of civil and family cases. SLS does not provide free legal assistance in cases seeking money damages. Those are cases that private lawyers may take on a contingent fee basis, which means they will take a percentage—usually up to one third of the damages—as their fee.
- Older Americans Act Another major source of federal LTSS funds is the Older Americans Act (OAA), enacted in 1965 to promote the well being of older persons and help them remain independent in their communities. The OAA provides federal funds to pay for home and community-based LTSS for older adults, generally 60 and older, and their families. States are required to target assistance to persons with the greatest social or economic need. Services funded under this Act include information and referral, counseling, outreach, congregate meal sites and home-delivered meals, transportation, long-term care ombudsman services, legal services, elderly protective services, and employment services programs for older adults.

The federal Administration on Aging provided \$17.6 million in FFY 2011 to the DSS Aging Services Division. Of these funds, \$16 million were distributed by formula to the Area Agencies on Aging who in turn contract with community-based organizations to provide social and nutritional services. The remaining \$1.6 million of these funds were special grants received by Aging Services, including Aging and Disability Resource Centers, Empowering Older People to Take Control of Their Health (Evidence-Based Health Promotion), Alzheimer’s disease and Supportive Services, and Elder Abuse Prevention. Both federal and State funds for Aging Services provided a multitude of services to 77,317 seniors.

### **Long-Term Care Housing Options**

- Congregate Housing Services Congregate housing provides frail older adults with private living arrangements, moderate supportive services, and common areas of dining, socialization and other activities. These facilities furnish at least one daily meal, which is usually included in the monthly fee, housekeeping services and a variety of social and recreational activities. They are generally meant for individuals who are basically self-sufficient but need a few services to help them to live independently.
- Alzheimer’s Special Care Units (see Appendix, CGS 19a-562a)
- Assisted Living Facilities Assisted Living Services Agencies (ALSAs) are an alternative for older adults who need assistance with activities of daily living (e.g. bathing, dressing), but who do not require the intensive medical and nursing care provided in a nursing facility. In Connecticut, ALSAs are licensed to provide assisted living services in managed residential communities (MRCs). Assisted living services can be provided in a number of different settings, such as continuing care retirement communities or elderly housing, as long as the

facility provides the services to qualify as a MRC. Services provided by the MRC include laundry, transportation, housekeeping, meals, and recreational activities. Individuals choosing to live in an MRC may purchase LTSS from the ALSA allowing them to live in their own apartment. Primarily, assisted living services in the MRC are available to individuals age 55 and older.

- Skilled Nursing Facilities Nursing facilities provide personal and skilled nursing care 24 hours a day. This level of care is often used when an individual has a condition that requires 24-hour supervision, substantial needs based on activities of daily living (ADL) or cognitive status, inadequate informal support, or insufficient financial resources to pay for home and community-based services. In addition to serving long-term services and supports needs, nursing facilities are also relied upon for short term post-acute rehabilitation services. There are two types of nursing facilities licensed in Connecticut: chronic and convalescent nursing facilities (skilled nursing facilities) and rest homes with nursing supervision.
- Residential Care Homes Residential care homes are facilities that provide a room, meals and supervision, but no nursing services, for individuals whose limitations prevent them from living alone. Services vary from facility to facility but may include dietary and housekeeping services, monitoring of prescription medication, social and recreational opportunities, and assistance with activities of daily living. Residential care homes in Connecticut are licensed by DPH. As of June 30, 2012, there were 101 residential care homes in Connecticut with a total of 2,763 beds.

#### Residential Settings for Individuals with Intellectual Disability

- Individualized Home Supports -- Some people need minimal hours of staff support to live in their own place or family home. This staff support may be in the form of assistance with budgets, shopping and/or leisure activities. People receiving Individualized Home Supports get staff support from a few hours a day to only a few hours a month, depending on the needs of the person. On June 30, 2012, 2,733 individuals received Individualized Home Supports.
- Community Companion Homes -- People with intellectual disability live in a family setting that is not within their own family. People in these settings live with a family that has received training and licensing from DDS. On June 30, 2012, 401 individuals lived in Community Companion Homes.
- Continuous Residential Supports-- People who need overnight support and live with three or fewer people share an apartment or house and have staff from an agency or hired privately. On June 30, 2012, 450 individuals lived in Continuous Residential Supports.
- Community Living Arrangements -- People who need 24 hour support are provided with staff in group home settings. Usually, two to six people share an apartment or house and have staff available to them 24 hours a day.

#### **Home Care Services**

In Connecticut, paid home care services are provided by home health care agencies, homemaker-home health aide agencies, homemaker-companion agencies, and privately hired caregivers.

- Home health care agencies, which are licensed by DPH, provide care in the home that is typically prescribed by an individual's physician as part of a written plan of care. These agencies offer skilled nursing, home health aide services, physical therapy, occupational therapy, speech therapy, and hospice services. Non-medical services include helping individuals with activities of daily living such as bathing, dressing and eating; assistance with cooking, cleaning, and other housekeeping jobs; and managing medications. Although home health care may include some non-medical home care services such as homemakers and companions, home health care is more medically oriented, helping individuals recover from an illness or injury. Home health care agencies, unlike homemaker-home health aide agencies and homemaker-companion agencies, may be eligible for Medicare reimbursement. As of June 30, 2012, there were 101 agencies licensed by DPH to provide home health care services in Connecticut.
- Homemaker-home health aide agencies, which are licensed by DPH, are similar to homemaker-companion agencies in that they provide non-medical assistance to individuals. In addition, they have the authority to provide training programs and competency evaluations for home health aides. As of June 30, 2012, there were 7 licensed agencies in Connecticut.
- Homemaker-companion agencies provide non-medical assistance to persons with disabilities and older adults and must be registered with the Department of Consumer Protection. Tasks generally include grocery shopping, meal preparation, laundry, light housekeeping and transportation to appointments. As of June 30, 2012, there were 375 registered homemaker-companion agencies active in Connecticut.
- Privately hired caregivers often provide personal care and are hired directly by an individual in need of support. The individual who hires them is the employer and is responsible for paying for unemployment, social security, workers compensation, taxes and liability insurance.

### **Veterans and Surviving Spouses**

- Veteran's Affairs The federal Department of Veterans Affairs (VA) pays for LTSS for service-related disabilities and for certain other eligible veterans, and other health programs such as nursing facility care and at-home care for aging veterans with LTSS needs. Veterans who do not have service-related disabilities but who are unable to pay for the cost of necessary care may also receive LTSS. In Connecticut, the VA funds a Veteran Directed Home and Community Based Services (VDHCBS) program through the Department of Social Services. Veterans served through this program have the opportunity to self-direct their own care and receive services in their home by the caregiver of their choice. The Sgt. John L. Levitow Veterans' Health Center at the Connecticut State Veterans' Home provides long term quality health care to veterans with chronic and disabling medical conditions. These conditions include, but are not limited to, chronic obstructive pulmonary disease (COPD), congestive heart disease (CHF), Cardiovascular Accident, Parkinson's disease, Alzheimer's disease and other dementias. The facility also provides End-of-Life care, Palliative care and Respite care. The Health Center is licensed by the Department of Public Health as a Chronic Disease Hospital and is recognized by the U.S. Department of Veterans' Affairs as a Nursing Facility.



- *Aid and Attendance Pension Program*-a veteran or a surviving spouse of a veteran can get additional payments for long term care in an assisted living facility, in a nursing home or at home with a home care program if the service, disability, and financial requirements are fulfilled. Available to any veteran and surviving spouse who requires the “aid and attendance” of another person in order to, “avoid the hazards of his or her daily life.”
- *Gatekeeper Program* The Gatekeeper Program educates the community (postal workers, hairdressers, etc.) to identify and refer older adults who may be in need of assistance to remain safe in their homes. The statewide program aims to connect seniors who need assistance with programs that could help them, including medical, social and mental health services. It relies on neighbors, family, mail carriers, hairdressers and others who encounter seniors to make referrals, then dispatches social workers to assess the situation and refer people to any services that are appropriate. The program includes education about signs of problems for people likely to come into contact with seniors, including postal workers, meals-on-wheels delivery workers, residential property managers, visiting nurses and seniors. The program began as a pilot in 2009 by St. Luke's Veterans and Eldercare Services in Middletown and has been funded statewide by the state Department of Mental Health and Addiction Services.

## Appendix D: Statutes and Regulations

### Special Act No. 13-11

#### **AN ACT ESTABLISHING A TASK FORCE ON ALZHEIMER'S DISEASE AND DEMENTIA.**

Be it enacted by the Senate and House of Representatives in General Assembly convened:

Section 1. (*Effective from passage*) (a) There is established a task force to study the care provided to persons diagnosed with Alzheimer's disease and dementia in the state. The task force shall analyze and make recommendations on the subject of Alzheimer's disease and dementia that shall include, but need not be limited to: (1) Services provided to persons diagnosed with Alzheimer's disease and dementia, including persons with early-stage and early-onset of Alzheimer's disease, and such persons' family members and caregivers; (2) legislative policy changes to better serve such persons, family members and caregivers; (3) coordination between state agencies and private community-based health care providers to serve such persons, family members and caregivers; (4) case management services for such persons, family members and caregivers; (5) the transition of such persons from one health care facility to another; and (6) the placement of such persons in community-based settings or health care facilities other than nursing home facilities, when feasible.

(b) The task force shall consist of the following members:

(1) The chairpersons and ranking members of the joint standing committees of the General Assembly having cognizance of matters relating to aging and public health, or the chairpersons' and ranking members' designees;

(2) One appointed by the speaker of the House of Representatives, who shall be a person diagnosed with Alzheimer's disease;

(3) One appointed by the president pro tempore of the Senate, who shall be a family member of, and caregiver for, a person diagnosed with Alzheimer's disease;

(4) One appointed by the majority leader of the House of Representatives, who shall be a representative of an organization that advocates for persons with Alzheimer's disease and dementia who are living in long-term care facilities;

(5) One appointed by the majority leader of the Senate, who shall be a physician whose practice is focused on the treatment of elderly patients;

(6) One appointed by the minority leader of the House of Representatives, who shall be a representative of a community-based health care provider;

(7) One appointed by the minority leader of the Senate, who shall be a member of the Alzheimer's Association, Connecticut Chapter;

(8) One appointed by the Governor, who shall be a representative of a long-term care facility;

(g) The chairperson of the Long-Term Care Planning Committee, established pursuant to section 17b-337 of the general statutes;

(10) The Commissioners of Social Services, Public Health and Emergency Services and Public Protection, the Commissioner on Aging and the Labor Commissioner and Banking Commissioner, or said commissioners' designees; and

(11) The Probate Court Administrator, or the administrator's designee.

(c) Any member of the task force under subdivision (1) or subdivisions (3) to (7), inclusive, of subsection (b) of this section may be a member of the General Assembly.

(d) All appointments to the task force shall be made not later than thirty days after the effective date of this section. Any vacancy shall be filled by the appointing authority.

(e) The president pro tempore of the Senate and the speaker of the House of Representatives shall each appoint one chairperson of the task force from among the members. Such chairpersons shall schedule the first meeting of the task force, which shall be held not later than sixty days after the effective date of this section. A majority of the task force members shall constitute a quorum. A majority vote of a quorum shall be required for any official action of the task force. The task force shall meet upon the call of the chairs or upon the request of a majority of the members.

(f) The administrative staff of the Commission on Aging shall serve as administrative staff of the task force.

(g) Members of the task force shall serve without compensation, except for necessary expenses incurred in the performance of their duties.

(h) Not later than January 1, 2014, the task force shall submit a report, in accordance with the provisions of section 11-4a of the general statutes, on its findings and recommendations to the joint standing committees of the General Assembly having cognizance of matters relating to public health and aging. The task force shall terminate on the date that it submits such report or January 1, 2014, whichever is later.

Approved June 18, 2013

#### CGS § 19a-562

#### **Alzheimer's special care units or programs. Definitions. Disclosure requirements.**

(a) As used in this section and section 19a-562a, "Alzheimer's special care unit or program" means any nursing facility, residential care home, assisted living facility, adult congregate living facility, adult day care center, hospice or adult foster home that locks, secures, segregates or provides a special program or unit for residents with a diagnosis of probable Alzheimer's disease, dementia or other similar disorder, in order to prevent or limit access by a resident outside the designated or separated area, or that advertises or markets the facility as providing specialized care or services for persons suffering from Alzheimer's disease or dementia.

(b) On and after January 1, 2007, each Alzheimer's special care unit or program shall provide written disclosure to any person who will be placed in such a unit or program or to that person's legal representative or other responsible party. Such disclosure shall be signed by the patient or responsible party and shall explain what additional care and treatment or specialized program will be provided in the Alzheimer's special care unit or program that is distinct from the care and treatment required by applicable licensing rules and regulations, including, but not limited to:

(1) Philosophy. A written statement of the overall philosophy and mission of the Alzheimer's special care unit or program that reflects the needs of residents with Alzheimer's disease, dementia or other similar disorders.

(2) Preadmission, admission and discharge. The process and criteria for placement within or transfer or discharge from the Alzheimer's special care unit or program.

(3) Assessment, care planning and implementation. The process used for assessing and establishing and implementing the plan of care, including the method by which the plan of care is modified in response to changes in condition.

(4) Staffing patterns and training ratios. The nature and extent of staff coverage, including staff to patient ratios and staff training and continuing education.

(5) Physical environment. The physical environment and design features appropriate to support the functioning of cognitively impaired adult residents.

(6) Residents' activities. The frequency and types of resident activities and the ratio of residents to recreation staff.

(7) Family role in care. The involvement of families and family support programs.

(8) Program costs. The cost of care and any additional fees.

(c) Each Alzheimer's special care unit or program shall develop a standard disclosure form for compliance with subsection (b) of this section and shall annually review and verify the accuracy of the information provided by Alzheimer's special care units or programs. Each Alzheimer's special care unit or program shall update any significant change to the information reported pursuant to subsection (b) of this section not later than thirty days after such change.

#### CGS § 19a-562a

#### **Pain recognition and management training requirements for nursing home facility staff. Staff training requirements for Alzheimer's special care units or programs.**

(a) Each nursing home facility that is not a residential care home or an Alzheimer's special care unit or program shall annually provide a minimum of two hours of training in pain recognition and administration of pain management techniques to all licensed and registered direct care staff and nurse's aides who provide direct patient care to residents.

(b) Each Alzheimer's special care unit or program shall annually provide Alzheimer's and dementia specific training to all licensed and registered direct care staff and nurse's aides who provide direct patient care to residents enrolled in the Alzheimer's special care unit or program. Such requirements shall include, but not be limited to, (1) not less than eight hours of dementia-specific training, which shall be completed not later than six months after the date of employment and not less than eight hours of such training annually thereafter, and (2) annual training of not less than two hours in pain recognition and administration of pain management techniques for direct care staff.

(c) Each Alzheimer's special care unit or program shall annually provide a minimum of one hour of Alzheimer's and dementia specific training to all unlicensed and unregistered staff, except nurse's aides, who provide services and care to residents enrolled in the Alzheimer's special care unit or program. For such staff hired on or after October 1, 2007, such training shall be completed not later than six months after the date of employment.

**CGS § 19a-522c**

**Chronic and convalescent nursing homes and rest homes with nursing supervision: In-service training.**

A nursing home administrator of a chronic and convalescent nursing home or a rest home with nursing supervision shall ensure that all facility staff receive annual in-service training in an area specific to the needs of the patient population at such facilities. A nursing home administrator shall ensure that any person conducting the in-service training is familiar with needs of the patient population at the facility, provided such training need not be conducted by a qualified social worker or qualified social worker consultant. In accordance with section 19a-36, the Commissioner of Public Health shall amend the Public Health Code in conformity with the provisions of this section.

**CGS § 19a-519-1**

**Nursing Home Administrator—Educational & Licensure Requirements**

Definitions. As used in these regulations, the following terms shall have the meanings specified.

(a) "Accredited institution of higher education" means an institution which has received accreditation to grant post-secondary degrees from one of the following regional accrediting bodies: New England Association of Schools and Colleges; Middle States Association of Colleges and Schools; North Central Association of Colleges and Schools; Northwest Association of Schools and Colleges; Southern Association of Colleges and Schools; and Western Association of Schools and Colleges.

(b) "Commissioner" means the Commissioner of Health Services or his designee.

(c) "Department" means the Department of Health Services.

(d) "Program director" means the individual responsible for developing and administering an approved educational and training program at an accredited institution of higher education.

(e) “Business Affiliation” means having a financial, or personal beneficial, interest in or having any type of employment or contractual relationship with the long-term care facility or hospital within the two years immediately preceding the beginning of the residency training.

(f) “Familial Affiliation” means having a spouse, child, child’s spouse, parent, brother, or sister who is either an officer, director, owner, limited or general partner, or holds more than 5% of outstanding stock in a facility.

(g) “Applying for licensure” means submitting a completed application and such supporting documentation as are sufficient to satisfy licensure eligibility requirements as determined by the Department.

(Effective October 30, 1987)

#### **CGS § 19a-519-2**

#### **Course in long-term care administration**

A course in long term care administration, as used in Section 19a-512 of the Connecticut General Statutes, shall consist of two components: academic instruction in long term care administration and residency training in long term care administration.

(a) A course in long term care administration offered by an educational institution in Connecticut must be approved pursuant to Section 19a-519-4 of these regulations.

(b) The academic component of a course in long term care administration shall consist of a minimum of three (3) semester credit hours, or equivalent, of academic instruction in Administration and Management of Long Term Care Facilities within an accredited institution of higher education and shall include the following content areas: General Administration and Management of Long Term Care Facilities; Financial Management of Long Term Care Facilities; Laws and Regulations Governing Long Term Care Facilities; Personnel Management and Labor Relations in Long Term Care Facilities; Patient Care and Services; Long Term Care Planning and Delivery Systems; and Gerontology.

(c) The residency training in long term care administration, also referred to as the one year residency period required by Connecticut General Statutes Section 19a-512 (a) (2), shall consist of a program of at least nine hundred (900) clock hours of administrative training in a long-term care facility providing skilled nursing care twenty-four hours per day under medical supervision and direction, and shall be completed under the joint supervision and direction of a licensed nursing home administrator in such facility and the program director. Such program shall include the following areas of experience: Administration, including Business Office, Human Resources, Management Information Processing, Marketing, Planning and Public Relations; Staff Development; Nursing Services; Medical and Professional Services; Rehabilitative Services, including Physical Therapy, Occupational Therapy, and Speech Therapy; Social Services; Medical Records; Recreation Therapy; Dietetics; and Physical Plant, including Maintenance, Housekeeping, Central Supply, and Laundry.

(d) In all cases, the trainee must receive approval of residency training from the program director prior to beginning the training. A minimum of four hundred fifty (450) clock hours of residency training shall be completed in a long-term care facility with which the trainee has no

business or familial affiliation. Upon the prior written approval of the program director, the remaining four hundred fifty (450) clock hours can be completed in a facility where a business or familial affiliation does exist. A minimum of twenty (20) hours of residency training must be completed each week.

(e) The residency training shall not commence prior to the approved academic instruction. The residency training may commence concurrent with the approved academic instruction with the prior written approval of the program director.  
(Effective October 30, 1987)

### **Sec. 19a-519-3 Masters' degree requirements**

(a) A master's degree program offered by an educational institution in Connecticut for Nursing Home Administrator licensure in Connecticut must be approved pursuant to Section 19a-519-4 of these regulations.

(b) The master's degree referenced in Connecticut General Statutes Section 19a-512 (b) (2) (B) shall either be accredited by the Accrediting Commission On Education For Health Services Administration or consist of: (1) a minimum of forty five (45) semester hours of graduate level study completed in an accredited institution of higher education. A minimum of fifteen (15) of the forty-five (45) semester hours shall be classroom instruction within the area of health care administration. The coursework in health care administration shall include, but not necessarily be limited to, the following areas of administration of health care facilities: General Administration and Management of Health Care Facilities; Laws and Regulations Governing Health Care Facilities; Financial Management; Personnel Management and Labor Relations; Patient Care and Services; Health Care Planning and Delivery Systems; and Gerontology; and (2) a supervised field experience of at least five hundred (500) clock hours of training in the overall operation and administration of a hospital providing inpatient medical services or of a long term care facility providing skilled nursing care twenty-four hours per day under medical supervision and direction. Such experience shall be obtained in a facility with which the trainee has no business or familial affiliation.  
(Effective May 21, 1990)

### **Sec. 19a-519-4 Program approval**

Program approval shall be administered as follows:

(a) Initial approval shall be granted to a program in the following manner:

(1) The program shall provide to the Commissioner:

(A) Written notice of intent to seek program approval;

(B) A feasibility study for the planned program, which shall include discussion of at least the following:

(i) Applicant pool;

(ii) Graduate employment opportunities;

(iii) Educational and training facilities to be utilized;

(iv) Funding sources to be utilized

(C) A plan for the employment of program director and faculty. The plan shall specify the numbers and types of staff to be employed, the requisite qualifications of such staff, the timelines for employment of such staff, and projected future staffing needs.

(D) A comprehensive plan for the development and implementation of the educational program, including admission policies, educational objectives, curricula, course outlines, course sequences, graduation requirements, staffing, residency training or field experience sites, residency training or field experience supervisors, timelines, and a systematic self-evaluation plan;

(E) Any other information that the Commissioner may reasonably request.

(2) Pending satisfactory reviews of the program's educational standards, such initial approval shall remain in effect until the results of the first two licensure exams for program participants are available. However, the Commissioner shall have the discretion to conduct an earlier re-evaluation of program approval status should educational deficiencies become apparent during the period of initial approval.

(3) Acceptable program graduate performance shall be defined as at least an average of 80% of all program graduates who take the exam within any one year period successfully passing the licensing exam.

(4) Initial approval can only be retained for a maximum of eighteen months from the date of first program graduate.

(5) Conditional approval may be granted for one year to a program previously having initial or full approval if:

(A) The graduates of the program fail to achieve the standards prescribed in subsection (a) (3) of this section; or

(B) The program has initiated a major change from the approved plan pursuant to subsection (d) of this section.

(C) The program is not administered in a manner consistent with these regulations.

(6) Special progress reports shall be required of programs under conditional approval status.

(b) Full approval is granted by the Commissioner after the initial or conditional approval based on evidence that the program is meeting its educational objectives as demonstrated by graduates' performance, as defined in subsection (a) (3) of this section and that the program has maintained compliance with these regulations.

(c) The Commissioner, after a hearing, may remove a program from the list of approved programs when:

(1) The program has been on conditional approval for at least one year and has failed to correct identified deficiencies which caused it to be placed on conditional status;

(2) The Commissioner provides written notice of such hearing to the program director setting forth the particular reasons for the proposed action and fixing a date, not less than thirty



days from the date of such written notice, at which time representatives of the program will have an opportunity for a hearing;

(3) Upon completion of the hearing, the commissioner makes a decision regarding what action should be taken regarding the program;

(d) When a change is sought in the program director, faculty, curriculum or training experiences, the previously approved program must remain in place until the new program is approved by the Commissioner. Notice of such change shall be sent to the Commissioner accompanied by:

- (1) Rationale for change;
  - (2) Concise presentation of current vs. proposed program;
  - (3) Explanation of the effects of changes on:
    - (i) Currently enrolled students;
    - (ii) Functions and roles of graduates of new program.
  - (4) Timetable for implementation of change.
- (Effective October 30, 1987)

#### **Sec. 19a-519-5**

Repealed, May 21, 1990.

#### **Sec. 19a-519-6- Licensure of applicants licensed in other states**

(a) Applicants seeking Connecticut licensure under this section shall be currently licensed competent nursing home administrators in good standing in another state.

(b) Applicants under this section who have completed an administrator training program approved by the appropriate regulatory body of another state and equal to the training program required in this state may have that training accepted in lieu of the approved residency training requirement of Section 19a-519-2 of these regulations.

(c) Applicants under this section who have not completed an approved training program may have their licensed work experience accepted in lieu of the approved residency training requirement if they have been licensed and working full-time as the administrative head of a long term care facility providing skilled nursing services twenty four hours per day under medical supervision and direction for at least one year in such other state.

(d) Applicants under this section who hold a master's degree which lacks either course work or supervised field experience requirements may take supplemental coursework or supervised field experience to address those deficiencies. Such supplemental coursework or supervised field experience shall be approved in advance by the Department.  
(Effective October 30, 1987)

#### **Sec. 19a-519-7- Reinstatement**

A person previously licensed as a Nursing Home Administrator whose license has become void may apply for licensure pursuant to the provisions of Sections 19a-14-1 to 19a-14-5, inclusive, of the Regulations of Connecticut State Agencies. (Effective October 30, 1987)

**Connecticut Public Health Code Sec. 19-13-D69 (d), et seq.**

State law does not require the licensure or certification of home health aides, but home health care agencies must be licensed by the Department of Public Health (DPH). Under state regulation, home health aides providing services on behalf of homemaker-home health aide agency or home health care agency must complete a (1) DPH approved training program of at least 75 hours; (2) competency evaluation. The 75 hour training does specifically require dementia training, but does require teaching of “ways to work with the population served”.

Each facility or agency (i.e. residential care homes, assisted living facilities, adult congregate living facilities, adult day care centers, hospice, home health agencies) have their own applicable public health code that would need to be reviewed and revised to require dementia-specific training with the exception of homemaker/companion agencies that are only required to be registered with the Department of Consumer Protection.

**CGS § 7-2940**

**Sec. 7-2940. Development and implementation of policy re missing person reports. Training.**

(a) Not later than January 1, 2012, the Police Officer Standards and Training Council shall develop and implement a policy concerning the acceptance of missing person reports, including, but not limited to, missing adult person reports, by law enforcement agencies in this state and such agencies' response thereto. Such policy shall include, but not be limited to, (1) guidelines for the acceptance of a missing person report, (2) the types of information that a law enforcement agency should seek to ascertain and record concerning the missing person or missing adult person that would aid in locating the missing person or missing adult person, (3) the circumstances that indicate that a missing person or missing adult person is a high risk missing person, (4) the types of information that a law enforcement agency should provide to the person making the missing person report, to a family member or to any other person in a position to assist the law enforcement agency in its efforts to locate the missing person or missing adult person, and (5) the responsibilities of a law enforcement agency in responding to a missing person report and the manner of such response, including preferred methods of response that are sensitive to the emotions of the person making such report.

(b) Each police basic or review training program conducted or administered by the Division of State Police within the Department of Emergency Services and Public Protection, the Police Officer Standards and Training Council or a municipal police department shall include training in the policy developed pursuant to subsection (a) of this section and training in the use of the National Missing and Unidentified Persons System created by the Office of Justice Program's National Institute of Justice.