



Senate Bill 08-058

**COLORADO STATE
ALZHEIMER'S DISEASE PLAN**

A roadmap for Alzheimer's disease
caregiving and family support policies



November 2010

Governor Bill Ritter's Office
Members of the General Assembly
Department of Human Services
Department of Health Care Policy and Financing
Department of Public Health and the Environment
Department of Public Safety
Department of Labor and Employment

Senate Bill 08-058 authorized the formation of the Colorado Alzheimer's Coordinating Council (CACC) and appointed its members. The CACC is pleased to submit this final report in the form of an Alzheimer's State Plan to the Governor, General Assembly and participating state departments. This report presents the findings and recommendations of the CACC concerning the increasing incidence of Alzheimer's disease in Colorado, the state's current public and private capacity to address the care and service needs of individuals and families affected by Alzheimer's and makes recommendations for improvements to the current system in light of Colorado's rapidly aging population. The recommendations put forth in this plan will help to ensure that current gaps in care are addressed in the most efficient, cost effective and family friendly manner now and in future decades.

The Colorado Health Institute was contracted to facilitate and staff the CACC and therefore we present this document on its behalf. If you have any questions, please contact Tasia Sinn, research assistant, at sinnt@coloradohealthinstitute.org.

Pamela Hanes, PhD
(retired) President and CEO

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Colorado Alzheimer's Coordinating Council by Workgroup Affiliation

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Executive Summary

The prevalence of Alzheimer's disease is increasing both nationally and in Colorado. By 2050, the number of Americans with Alzheimer's disease is projected to exceed 13 million. More than 110,000 Coloradans are projected to have Alzheimer's disease in 2025, compared to 49,000 in 2000. Alzheimer's disease was the sixth-leading cause of death in Colorado in 2007. Further, according to the Alzheimer's Association (Association), it is estimated that 70 percent of nursing home residents have some degree of cognitive impairment. The Association also estimates that about 70 percent of individuals with Alzheimer's disease and related dementia live at home and receive care from family and friends. The current resources, information and long-term care services and supports for individuals with Alzheimer's disease are fragmented and underdeveloped in Colorado and require a coordinated and comprehensive state and community response.

In 2008, the Colorado General Assembly recognized the need for a state plan to address Alzheimer's disease and commissioned the Colorado Alzheimer's Coordinating Council (CACC) to complete this task (see Appendix A for a copy of SB 08-058). The CACC was instructed to draft a state plan that would describe the current status of the state, identify service and support gaps that exist and provide recommendations to state policymakers for needed improvements. This report shall serve as *Colorado's State Plan for Alzheimer's Disease*, in fulfillment of the mandate put forth in SB 08-058.

One of the major program areas identified by the Council was the lack of dementia-specific training for family caregivers, health care workers and facility staff. While Colorado recently passed legislation to require minimal training for personal care workers, many other health professions do not receive dementia-specific content in the course of their education and training. Alzheimer's disease and other dementia training is critical because of the unique nature of symptoms and management of the disease.

The following summarizes each chapter in the plan and outlines the recommendations put forth by the CACC. A more in-depth discussion of each recommendation, as well as strategies and timelines for its implementation, can be found in Chapter 6. The recommendations are in no particular order of priority.

Chapter I includes an overview of the charge to the CACC and background information about the characteristics of Alzheimer's disease and the population trends of disease prevalence in Colorado.

Alzheimer's disease: Characteristics and trends

- Alzheimer's disease (AD) is a progressive brain disorder that destroys brain cells, thereby causing a steady decline in memory, mental capacity and the ability to perform usual activities of daily living. As the disease progresses, it affects one's ability to remember, reason, learn and imagine. Loss of cognitive function caused by Alzheimer's disease is qualitatively different from that related to normal aging.
- On average, individuals with Alzheimer's disease live for eight to 10 years once a diagnosis has been established. There is no cure for Alzheimer's disease.

- The national Alzheimer’s Association has identified seven stages through which an individual with AD passes—ranging from no impairment to very severe cognitive decline.
- The youngest documented case of AD was age 26, and it is becoming more and more common to diagnose “young onset” cases under age 65. The prevalence is about three percent between ages 65 and 74, 20 percent between ages 75 and 84, and 50 percent over age 85.
- AD currently afflicts approximately five million Americans. Population aging is expected to result in a significant increase in the prevalence of Alzheimer’s disease. By 2050, the number of individuals with Alzheimer’s disease is projected to exceed 13 million.
- In 2000, approximately 49,000 Coloradans had Alzheimer’s disease; by 2025 this number will more than double (a 124% increase) to 110,000 individuals.¹ In 2010 there were 72,000 Coloradans with Alzheimer’s disease.
- Alzheimer’s disease was the sixth-leading cause of death in Colorado in 2007. Over 1,100 Coloradans died from Alzheimer’s disease which accounted for almost three percent of all deaths in 2007.
- The average annual per-capita Medicare expenditures for a beneficiary with Alzheimer’s disease or other dementia is three times that of one without Alzheimer’s disease or other dementia.
- Individuals 85 and older (the age group in which Alzheimer’s is most likely to occur) who live in households with incomes less than 200 percent of the federal poverty level spend 30 percent of their household income on out-of-pocket health expenditures, compared to 11 percent of individuals 85 and older in all other income categories.

Chapter 2 summarizes the availability of long-term care services and supports (LTSS) in Colorado. LTSS includes institutional care (nursing homes), home and community-based services (HCBS), support for family caregivers and end-of-life care. The long-term care (LTC) workforce is also discussed as an important aspect of LTSS.

Major LTSS findings

- All Colorado nursing homes must be licensed by the state, and, in the case of Medicare reimbursement, must also be certified by the Centers for Medicare and Medicaid Services (CMS). To receive Medicaid reimbursement, the nursing home must meet the CMS certification criteria for Medicare even if the home is not enrolled as a Medicare provider.
- In 2010, Colorado had 218 licensed skilled nursing facilities. Of Colorado’s 20,421 nursing home beds, approximately 81 percent were occupied in June 2010.²
- Colorado has 535 licensed assisted-living residences/assisted-living facilities (ALR/ACFs) with 16,350 available beds. ACFs include private pay and Medicaid residents with a separate class of residential treatment facilities for individuals with chronic and persistent mental illness.^{3, 4}
- In April 2010, there were 81 nursing homes and 101 ACFs offering a total of 4,143 secured beds for individuals with dementia in Colorado.^{5, 6}
- As of March 2010, Colorado had 67 Medicaid-certified adult day programs available through Colorado’s Medicaid HCBS waiver programs.ⁱ

ⁱ Home and Community-Based Service (HCBS) waivers are an array of long-term care supportive services funded by Medicaid and provided in a community setting with the goal of meeting the health, functional and behavioral

- Colorado Medicaid and Medicare both cover home health care services for qualified individuals.
- In 2005, Colorado had approximately 10,000 personal care assistants who help individuals with activities of daily living in their homes.
- The most common route into Colorado's formal LTC system is through one of 25 state-financed single entry points (SEPs) which are geographically dispersed around the state.
- Diagnosing Alzheimer's disease in the early stages can be difficult; however, an early diagnosis is beneficial for many reasons.⁷ In Colorado, the majority of diagnostic services are located in the metropolitan areas of the state.
- Hospice programs provide palliative care to terminally ill patients. In 2006, there were approximately 43 hospice programs operating in Colorado, with most certified to provide care to Medicare beneficiaries.⁸
- Although Colorado does not provide financial support for Alzheimer's disease research at any of the state's institutions of higher education, the University of Colorado is conducting a number of research investigations of the biological processes associated with Alzheimer's disease through private and federal support. The Neurology Department recently received a bequest of more than \$1.1 million to enhance research related to Alzheimer's disease. Colorado State University (CSU) researchers also conduct basic cellular and molecular biology research on dementia processes. CSU has also had \$3.3 million in federal funding from 2002 to 2012 to provide and evaluate AD caregiver training and interventions.

The long-term care workforce

- Approximately 42 percent of the LTC workforce is comprised of nurses including registered nurses (RNs), licensed practical nurses (LPNs) and certified nurse aides (CNAs). Other clinicians such as physical therapists and social workers account for an additional 13 percent of the workforce, while unlicensed personal care attendants represent just over 11 percent.
- A well-documented shortage of LTC providers exists; high turnover rates, large numbers of job vacancies and difficulties in recruiting new workers characterize the industry.
- The nationwide demand for workers in nursing and residential care facilities is expected to increase by 21 percent between 2008 and 2018. The need for additional positions in home health care is expected to increase by 46 percent during this time period.
- Employment for RNs and LPNs in home health agencies is projected to grow by 33 percent between 2008 and 2018, while the demand for personal care attendants and home health aides is expected to grow by 54 percent and 63 percent respectively.
- Nurses in Colorado are not required to receive Alzheimer's-specific training prior to licensure, yet 79 percent of LPNs working in LTC settings expressed interest in additional geriatric training and 77 percent in training specific to Alzheimer's disease and related dementia.

Chapter 3 discusses the cost of care for individuals with Alzheimer's disease. The variety of sources used to pay for care, including public and private, as well as the economic value of unpaid caregiving are addressed.

health needs of low-income elders and individuals with disabilities who otherwise would be eligible for placement in a nursing home or other institutional care.

Financing Alzheimer's disease

- Total payments for care from all sources are three times higher for individuals with Alzheimer's disease and related dementia than for other older adults.
- Medicare pays for medically necessary limited skilled nursing care (100 days post-hospitalization) or home health care services. Medicare does not pay for non-skilled or custodial care which includes assistance with activities of daily living. In 2004, Medicare paid on average three times more for beneficiaries with Alzheimer's disease and related dementia than those without dementia.
- Medicaid financing is by far the largest single source of funding for long-term care (LTC) and, when combined with acute care for people with disabilities and the elderly, accounts for more than half of all Medicaid spending in Colorado. The Colorado Medicaid program spent more than \$863 million on institutional and community-based LTC in FY2007-08.⁹
- In Colorado, the number of individuals enrolled in Medicaid waivers increased slightly over the past three years—from 26,746 in FY 2005-06 to 30,738 in FY 2008-09. Over that same period, the number of individuals residing in a skilled nursing facility dropped slightly from 14,299 to 13,636.¹⁰
- In 2006, private health and LTC insurance funded only about 9 percent of long-term care spending nationally.
- In 2004, Medicare beneficiaries aged 65 and older with Alzheimer's disease and related dementia had average out-of-pocket costs of \$2,464 annually; on average, individuals living out of home in a nursing home or assisted-living facility paid out-of-pocket costs of \$16,689 per person annually.¹¹

Unpaid caregiving

- Approximately three-quarters of adults who need LTC receive it from informal caregivers such as family members and friends.
- Between 2000 and 2050, the demand for formal caregivers is expected to increase from 1.8 million to 3.5 million caregivers; in contrast, the demand for informal caregivers is expected to grow from 21.6 million in 2000 to 40.1 million caregivers by 2050.¹²
- In 2009, 161,600 unpaid caregivers provided more than 184 million hours of personal care and assistance to individuals with Alzheimer's disease and related dementia in Colorado.
- The total economic value placed on informal caregiving for individuals with Alzheimer's disease and related dementia in Colorado is approximately \$2.1 billion annually.¹³

Chapter 4 discusses quality of life and quality of care measures and how the state and other organizations are addressing and monitoring quality of care in Colorado.

Quality of care and quality of life

- Quality measures are generally thought about in two ways. The medical perspective takes into account the medical needs of an individual and the quality of care received to meet those needs. Quality of life is a person-centered concept that takes into account not only medical needs, but also the social, spiritual and emotional dimensions of an individual's life.
- The Colorado Department of Public Health and the Environment regulates and monitors compliance of Colorado facilities, including hospitals, nursing homes, hospice, ACFs and home

care agencies. Nursing homes are inspected once a year, on average, as required by the federal government and home care agencies are inspected about once every three years.

- Research conducted by the Alzheimer’s Association found that proper training is essential to quality care. However, Colorado does not require caregivers of any type to receive dementia-related training.
- There are several programs in Colorado designed to train caregivers and facility staff in dementia care, including those at universities and programs offered through the Colorado Chapter of the Alzheimer’s Association, but there is no current incentive to require or provide strong incentives for people to pursue the training.
- Metrics for measuring *quality of care* developed by the National Quality Forum include measures such as the prevalence of urinary tract infections and the average risk of acquiring a pressure sore.
- Metrics for measuring *quality of life* developed by the Wisconsin Department of Health and Family services are stated in the first person and include such thing as “I participate to my capacity in all decisions affecting my life” and “I am useful and make contributions of value.”

Chapter 5 outlines the issues related to public safety for people with Alzheimer’s disease as well as discusses public awareness campaigns underway in Colorado.

Public safety and awareness

- Wandering is one of the most significant risks to individuals with Alzheimer’s disease—nearly 60 percent of people with Alzheimer’s wander at some point during the course of the disease. Approximately half of wanderings lead to injury if the individual is not found within 24 hours.
- In 2007, Colorado implemented a coordinated response system, similar to the Amber Alert for missing children, to report missing older adults.
- Driving also poses a risk to the individual with Alzheimer’s disease as well as a public safety risk. Currently, the Colorado Department of Motor Vehicles has the authority to cancel, deny or deny reissuance of a license for several reasons, including the inability to operate a motor vehicle because of physical or mental incompetence.

Chapter 6 discusses identified service and awareness gaps in Colorado and provides recommendations to state policymakers. The recommendations discuss which entities should be responsible for carrying out the recommendation, how much they will cost and specific timelines for each recommendation. The recommendations align with the four issue-specific workgroups of the CACC. This chapter also outlines best practices from elsewhere in the country. The recommendations are as follows:

Formal services/workforce development

- *Recommendation 1.1.* Create a state certification in dementia care for facilities, agencies and individuals licensed and monitored by the Colorado Department of Health and the Environment and the state health professions’ licensing boards.
- *Recommendation 1.2.* Provide targeted opportunities through scholarships and loan repayment programs for geriatric training through the National Health Service Corps and the Colorado Health Service Corps.

- *Recommendation 1.3.* Apply for a federal grant to create at least one new Geriatric Education Center in Colorado.
- *Recommendation 1.4.* Launch an information campaign to encourage individuals and organizations to apply for grants made available through national health reform to increase educational programs and the number of individuals who are competent to work with older adults who need supportive services with a focus on those with Alzheimer’s disease and related dementia.
- *Recommendation 1.5.* Test new models and expand evidence-based best practices in alternative care facilities caring for individuals with Alzheimer’s disease.

Informal services and caregiver support

- *Recommendation 2.1.* Create a statewide list of licensed attorneys who agree to provide pro bono or reduced-fee elder law services to individuals with Alzheimer’s disease and their families.
- *Recommendation 2.2.* Develop and implement strategies such as increasing the number of dedicated staff to probate courts or creating a volunteer legal services program to monitor and support court-appointed guardianship and conservatorship concerns. Apply for federal grants available through the *Patient Protection and Affordable Care Act* to enhance these adult protective services in Colorado (HR 3590, Sec. 2042).
- *Recommendation 2.3.* Educate employers about the issues facing family caregivers and encourage them to establish workplace policies such as flextime, telecommuting, referral services and on-site support programs.
- *Recommendation 2.4.* Ensure that local Area Agencies on Aging (AAAs) are aware of and promote existing training materials available to family caregivers, especially those located in rural areas.
- *Recommendation 2.5.* Increase funding for and expand the reach of the *Savvy Caregiver* program and equivalent training programs for all stages of dementia.

Quality of care and Alzheimer’s disease research

- *Recommendation 3.1.* Add an Alzheimer’s module to the Colorado Behavior Risk Factor Surveillance Survey (BRFSS) to collect state-level data on the prevalence of Alzheimer’s disease and associated characteristics such as living arrangements, family and caregiver needs and responsibilities.
- *Recommendation 3.2.* Establish a Colorado Alzheimer’s Disease Research Center at the University of Colorado School of Medicine.
- *Recommendation 3.3.* Conduct an evidence-based review of transitions of care models with a focus on patients with Alzheimer’s disease and related dementia, with the intent of authorizing two or three pilot programs in Colorado to test best practice approaches.
- *Recommendation 3.4.* Establish a senior advisor on aging and long-term care in the Governor’s Office of Policy and Initiatives.
- *Recommendation 3.5.* Support the Seniors Mental Health Access Improvement Act of 2009, federal legislation to provide reimbursement to marriage and family therapists and mental health counselors under Part B of Medicare.

Public safety and public awareness

- *Recommendation 4.1.* Create and circulate a form that physicians and optometrists can fill out and send to the Driver Control/Traffic Records Section of the DMV.
- *Recommendation 4.2.* Collaborate with and leverage the national Alzheimer's Association's public awareness campaign and related efforts to encourage the utilization of public service announcements through local radio and televisions stations, as well as other public awareness venues.
- *Recommendation 4.3.* Increase the visibility and utilization of locator devices and programs.
- *Recommendation 4.4.* Implement a gatekeeper model of case finding throughout the state to identify individuals with Alzheimer's disease who are at risk in the community.
- *Recommendation 4.5* Encourage and enhance adequate training for first responders about medical and behavioral issues related to Alzheimer's disease and related dementias when responding to an emergency involving these individuals.

Chapter I: Introduction

THE COLORADO ALZHEIMER'S COORDINATING COUNCIL (CACC)

Authorized by Senate Bill 08-058, the Colorado Alzheimer's Coordinating Council (CACC) was charged with assessing the current and future impact of Alzheimer's disease in Colorado and formulating recommendations for a Colorado Alzheimer's State Plan.

The provisions of SB 08-058 specify that the Council shall:

- Assess the current and future impact of Alzheimer's disease on the residents of Colorado;
- Solicit and gather information necessary for review and discussion by the Council;
- Gather feedback from individuals and families affected by Alzheimer's disease as well as from the general public;
- Review the availability of existing industries, services and resources that address the needs of individuals with Alzheimer's disease, their families and caregivers;
- Develop a strategy to mobilize a state response to the increasing incidence of Alzheimer's disease in Colorado;
- Consider other issues related to Alzheimer's disease that are identified by the Council;
- Formulate a comprehensive state plan for addressing Alzheimer's disease that includes short- and long-term strategies for confronting the challenges presented by the rapid growth in the Alzheimer's disease population; and,
- Submit a report of its findings, date-specific recommendations for statutory, administrative and procedural changes to the governor, General Assembly and participating state departments in the form of a Colorado Alzheimer's State Plan.

Members of the Council were appointed by the legislature and the governor to represent a range of perspectives related to Alzheimer's disease from an individual diagnosed with early stage Alzheimer's disease to state agency representatives and publicly elected officials. The Colorado Health Institute (CHI) served as the convener and facilitator for the Council, providing analytical, research and report drafting support under the Council's direction.

The CACC held eight meetings from March 2009 to July 2010. Early meetings focused on a review of issues related to Alzheimer's disease, including the organization and financing of long-term care (LTC) supportive services, the regulatory framework that governs LTC programs and institutions, the LTC workforce and quality of care (background materials are provided in the appendices to this report). In January 2010, the Council formed four workgroups based on four key subgroupings of issues. Each workgroup met up to three times to develop recommendations in the areas of:

- Formal Services and Workforce Development
- Informal Services and Caregiver Support
- Quality of Care and Alzheimer's Disease Research

- Public Safety and Public Awareness.

The Council used a consensus-based approach to derive the recommendations contained in the final report. In a few cases where consensus was not reached, these issues are noted in the body of the report.

WHAT IS ALZHEIMER'S DISEASE?

Alzheimer's disease (AD) is a progressive brain disorder that destroys brain cells, causing a steady decline in memory, mental abilities and the ability to perform usual activities of daily living. As the disease progresses, it affects one's ability to remember, reason, learn and imagine. Alzheimer's disease is the most common form of dementia which includes a broad spectrum of brain disorders that cause memory loss severe enough to interfere with the normal routines of daily living. Loss of cognitive function caused by Alzheimer's disease is qualitatively different from that related to normal aging. On average, individuals with Alzheimer's disease live for eight to 10 years once a diagnosis has been established. The national Alzheimer's Association has identified seven stages through which an individual with AD passes.

Stage 1 – No impairment, normal functioning.

Stage 2 – Very mild cognitive decline (may be normal age-related memory lapses).

Stage 3 – Mild cognitive decline. Early stage AD can be diagnosed in some but not all individuals with associated symptoms.

Stage 4 – Moderate cognitive decline, diagnosable early-stage AD. An informed medical interview will detect clear deficiencies in memory, decreased capacity to perform complex tasks, reduced memory of one's personal history and tendency to withdraw socially or from mentally challenging situations.

Stage 5 – Moderate severe cognitive decline (mid-stage AD). Major gaps in memory and deficits in cognitive functioning emerge. Assistance with activities of daily living becomes essential. Very common facts such as current address and telephone number cannot be recalled upon medical examination, confusion about place and time, simple math difficult, retaining knowledge about self is lost and individual usually needs assistance with toileting and eating.

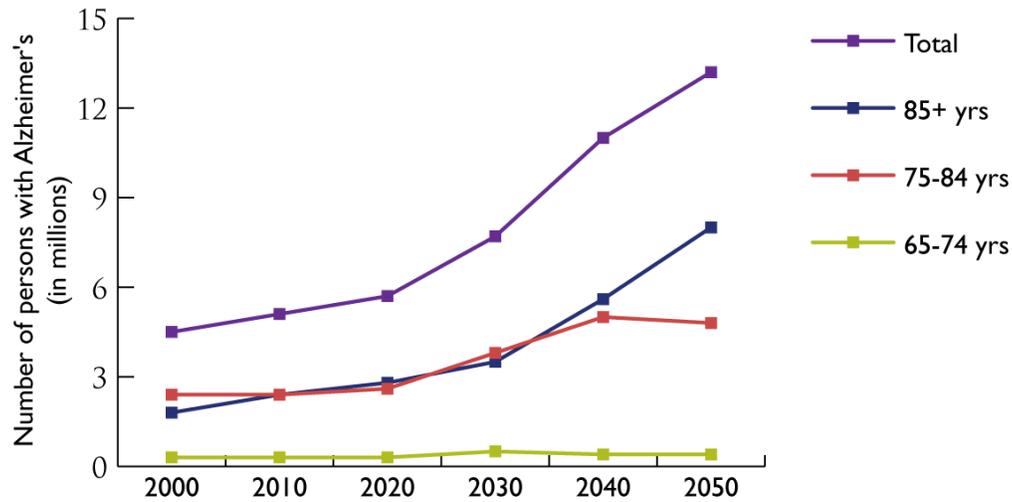
Stage 6 – Severe cognitive decline; can be severe, moderate or mid-stage AD upon diagnosis. Memory loss accelerates, personality changes emerge and more intense help with activities of daily living are needed. Wandering is common in this stage of the disease.

Stage 7 – Very severe cognitive decline; severe or late stage AD. This is the final stage of the disease; individuals lose their ability to respond to their environment, the ability to speak and ultimately, the ability to control movement.

PREVALENCE OF ALZHEIMER'S DISEASE: UNITED STATES AND COLORADO

Alzheimer's disease currently afflicts approximately five million Americans. Because the incidence of Alzheimer's disease is highly correlated with age, the aging of the population has significant implications for the resources needed to care for individuals with Alzheimer's disease. Population aging is expected to result in a significant increase in the prevalence of Alzheimer's disease— by 2050, the number of individuals with Alzheimer's disease is projected to exceed 13 million (Graph 1).

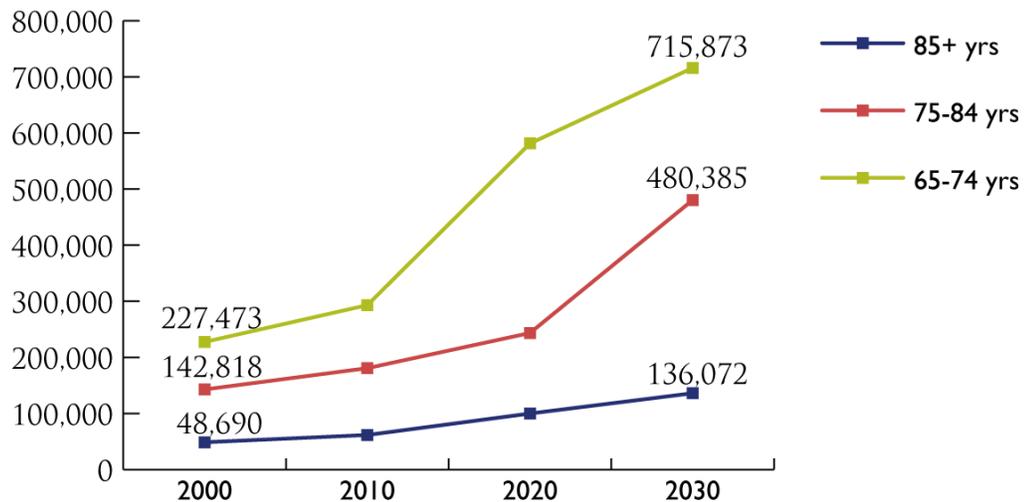
Graph I. Projected prevalence of Alzheimer's disease, by age group, U.S., 2000-50



SOURCE: Hebert, LE, et al. (2003). "Alzheimer Disease in the U.S. Population: Prevalence estimates using the 2000 Census." *Archives of Neurology* 60:1119-22.

The youngest documented case of Alzheimer's was age 26, and more and more "young onset" cases in those under 65 are diagnosed each year. The prevalence is about three percent between ages 65 and 74, 20 percent between ages 75 and 84, and 50 percent over age 85. In 2000, approximately 49,000 Coloradans had Alzheimer's disease; by 2025 this number will more than double (a 124% increase) to 110,000 individuals.¹⁴ Alzheimer's disease is most prevalent among older adults (ages 85 years and older) and women.¹⁵ Within the 65+ population in Colorado, the 85+ population in Colorado, at greatest risk for developing AD, will nearly triple in the next 20 years.

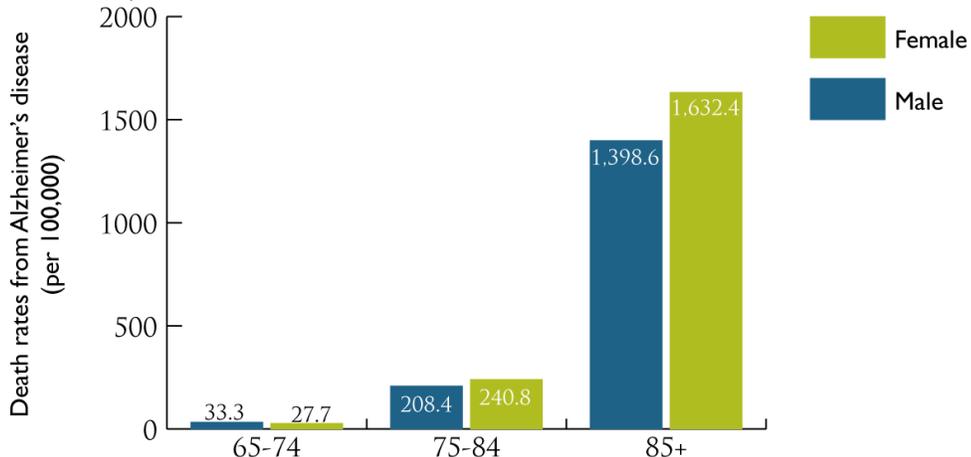
Graph 2. Colorado's population distribution for persons ages 65 years and older, 2000-30



SOURCE: Colorado State Demography Office, population estimates, 2000-30.

Alzheimer’s disease is a fatal disease. As noted earlier, the usual progression of the disease, once diagnosed, results in a life span of eight to 10 years post-diagnosis. Graph 3 summarizes Colorado death rates from Alzheimer’s disease based on age and gender.

Graph 3. Death rates from Alzheimer’s disease per 100,000 adults, by age group and gender, Colorado, 2008



SOURCE: Colorado Department of Public Health and Environment death statistics at: <http://www.cdphe.state.co.us/cohid/index.html>.

As Table I illustrates, not only has the *number* of deaths from Alzheimer’s disease increased in Colorado (from 709 in 2000 to 1,108 in 2007), but the age-adjusted death *rate*ⁱⁱ has increased from 22 deaths to nearly 31 deaths per 100,000 population during the same time period. Therefore, even after adjusting for the aging of the population, the death rate from Alzheimer’s disease is steadily increasing.

Table I. Number of deaths and death rates from Alzheimer’s disease, Colorado, 2000-08

Record year	Number of deaths due to Alzheimer's disease	Death rate per 100,000 population (age-adjusted)
2000	709	22.3
2001	849	26.4
2002	953	29.2
2003	897	27.0
2004	910	26.7
2005	1,062	30.6
2006	1,055	29.8
2007	1,108	36.6
2008	1,351	29.0

SOURCE: Colorado Department of Public Health and Environment at: <http://www.cdphe.state.co.us/cohid/index.html>.

ⁱⁱ The age-adjusted death rate is the rate that would exist if the population under study had been distributed by age in the same way as the general population.

Alzheimer’s disease was the sixth-leading cause of death in Colorado in 2007. More than 1,100 individuals in Colorado died from Alzheimer’s disease, accounting for almost four percent of all deaths in 2007.

Table 2. Leading causes of death, number of deaths and death rates, Colorado, 2007

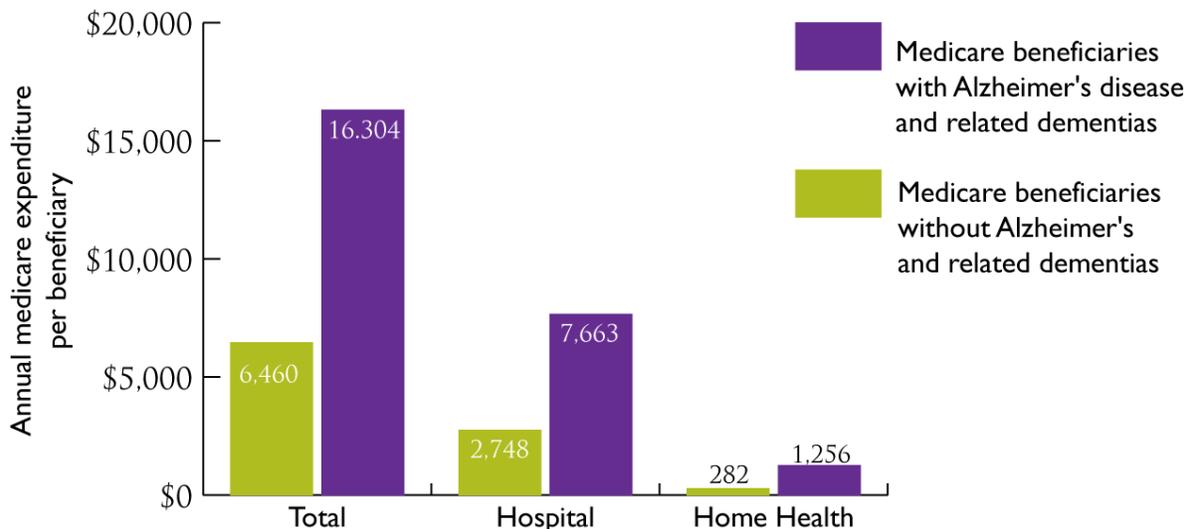
Rank	Cause of Death	Total number of deaths	Death rate per 100,000 population (age-adjusted)
	All Causes	29,888	736.5
1	Cancer	6,590	157.9
2	Heart disease	6,073	154.4
3	Unintentional injuries	2,029	44.7
4	Chronic lower respiratory diseases	1,997	51.4
5	Stroke	1,589	41.7
6	Alzheimer's disease	1,108	30.8

SOURCE: Colorado Department of Public Health and Environment at: <http://www.cdphe.state.co.us/cohid/index.html>.

ECONOMIC IMPACT OF ALZHEIMER’S DISEASE ON INDIVIDUALS, FAMILIES AND SOCIETY

The caregiving associated with Alzheimer’s disease is often resource intensive, particularly once the disease has progressed to stages five through seven. The average annual per-capita Medicare expenditures for a beneficiary with Alzheimer’s disease or other dementia is three times that of one without Alzheimer’s disease or other dementia. (Graph 4)

Graph 4. Average per-person payments for health care services, Medicare beneficiaries aged 65 and older with or without AD and other dementia, 2004



SOURCE: Created from Alzheimer’s Association. *Characteristics, Costs and health Service Use for Medicare Beneficiaries with a Dementia Diagnosis: Report 1: Medicare Current Beneficiary Survey, 2009* [78].

Age, health status and income have a significant effect on the vulnerability of an individual to out-of-pocket costs. Individuals 85 and older who are in the poor/near-poor income category spend 30 percent of their household income on out-of-pocket expenditures, compared to 11 percent of individuals 85 and older in all other income categories.

Table 3. Out-of-pocket health care expenditures as a percentage of household income among people age 65 and older, by select characteristics, 2000-04

Age		2000	2001	2002	2003	2004
Total						
	65 and over	9.1	10.0	10.8	11.6	11.6
	65-74 yrs	8.1	8.7	9.5	9.2	10.7
	75-84 yrs	10.4	11.4	11.9	13.4	11.8
	85 and over	10.1	11.8	12.7	16.4	14.9
Income category						
Poor/near poor (at or below 125% of federal poverty level)	65 and over	22.6	23.5	27.6	27.8	29.3
	65-74 yrs	24.4	25.7	27.7	23.4	29.0
	75-84 yrs	22.9	23.3	28.4	30.2	29.4
	85 and over	17.6	18.7	25.7	32.4	30.0
Other	65 and over	6.3	7.3	7.2	8.0	8.1
	65-74 yrs	5.6	6.2	6.4	6.9	7.4
	75-84 yrs	3.9	8.4	8.2	9.1	8.2
	85 and over	7.6	9.3	7.9	10.3	11.1
Health status category						
Poor or fair health	65 and over	13.1	13.9	14.6	16.0	15.2
	65-74 yrs	11.8	13.5	14.4	13.8	14.3
	75-84 yrs	14.6	14.7	15.2	17.5	15.4
	85 and over	13.8	13.2	13.5	19.5	17.9
Excellent, very good or good health	65 and over	6.7	7.6	8.4	8.9	9.4
	65-74 yrs	6.2	6.2	7.1	6.9	8.9
	75-84 yrs	7.5	9.1	9.6	10.7	9.3
	85 and over	7.1	10.6	11.9	13.9	12.8

SOURCE: Federal Interagency Forum on Aging-Related Statistics. (2008). *Older Americans 2008: Key Indicators of Well-Being*.

Chapter 2: Availability of Long-term Services and Supports in Colorado

Long-term services and supports (LTSS) can be grouped into two general categories—purchased formal services provided by agencies or institutions and unpaid informal care provided by families and friends. Formal care can be further divided into institutional care (nursing homes) and home and community-based services, including those provided in an alternative care facility.

Approximately three-quarters of adults who need LTSS receive it from informal caregivers, while an additional 14 percent receive a combination of informal and formal caregiving. Only 8 percent of adults needing LTSS receive it through the formal service system. It is estimated that an additional two percent of adults needing personal assistance go without. In the case of Alzheimer’s disease, particularly in the later stages of the disease, formal caregiving is more often required because of the almost total loss of ability to perform normal activities of daily living. In addition, palliative care and hospice play increasingly important roles in the care of individuals with Alzheimer’s disease and related dementia.

LONG-TERM CARE (LTC) FACILITIES: NURSING HOMES AND ALTERNATIVE CARE FACILITIES

Skilled nursing facilities (nursing homes) provide 24-hour nursing care and personal assistance in an institutional setting. In 2010, Colorado had 218 licensed skilled nursing facilities. All Colorado nursing homes must be licensed by the state. To receive Medicare reimbursement, they must also be certified by the Centers for Medicare and Medicaid Services (CMS), or, in the case of Medicaid reimbursement, they must meet CMS certification standards even if the facility is not enrolled in Medicare. Of Colorado’s 20,421 nursing home beds, approximately 81 percent were occupied in March 2010.¹⁶

Assisted-living residences, also known as alternative care facilities (ACFs) when they are approved for Medicaid participation, provide personal care assistance, protective oversight, social support services and 24-hour supervision for individuals with functional limitations to live as independently as possible in a community residential setting.¹⁷ Colorado has 535 licensed assisted-living residences with 16,350 beds available for individuals, including private pay and Medicaid residents and a separate class of residential treatment facilities for individuals with chronic and persistent mental illness.^{18, 19}

In Colorado, both nursing homes and assisted-living residences have the option to offer a secured environment specializing in services for residents with dementia and memory loss. These special care units provide residents with Alzheimer’s disease with better care and protect residents without dementia in nursing home and assisted-living settings. In April 2010, Colorado had 81 nursing home facilities and 101 assisted-living residencies offering a total of 4,143 secured beds for individuals with dementia.^{20, 21}

HOME AND COMMUNITY-BASED SERVICE (HCBS) WAIVERS

Home health care is provided by licensed home health care agencies which provide skilled nursing care, rehabilitation therapies, skilled personal care and social work services. In Colorado, Medicaid reimburses for the broad range of home health care services noted above. The Medicaid home health benefit is

available both to categorically eligibleⁱⁱⁱ individuals as well as to those who receive long-term care services under a Medicaid Home and Community-based Waiver program.

Medicare reimburses for the full range of home health care services from agencies that are certified by CMS. Medicare-reimbursed home health care must be authorized by a licensed physician, can only be provided on an intermittent basis and only to homebound individuals who are also receiving skilled nursing care in the home.²²

Medicaid-reimbursed home health care also must be authorized by a licensed physician but can be authorized on a long-term basis and does not require individuals to be homebound. Because state licensure of home care agencies is relatively new in Colorado, the precise number of licensed home care agencies is not available. The Colorado Department of Public Health and the Environment estimates there are between 550 and 600 home care agencies in Colorado.

Personal care services are typically provided by paraprofessionals, who may be certified nurse assistants (CNAs) or personal care attendants who have not received formal training. These workers provide assistance with activities of daily living and instrumental activities of daily living (ADLs and IADLs), including help with transferring from bed to wheelchair, feeding and grooming, meal preparation and household chores. In 2005, it was estimated that Colorado had a workforce of approximately 10,000 personal care workers.²³

Adult day programs include health and social services, personal care, therapies such as physical and occupational therapy, and mental health services that are provided on a daily or regularly scheduled basis in an adult day health center. As of March 2010, Colorado had 67 Medicaid-certified adult day programs, a service available through Colorado's Medicaid Home and Community-Based Waiver programs.^{iv} Adult day programs provide supportive services for individuals with Alzheimer's or other dementia, multiple sclerosis, brain injuries, chronic mental illness, developmental disability or post-stroke participants who require extensive rehabilitative therapies.

Program of All-inclusive Care for the Elderly (PACE) is a fully capitated (all-inclusive rate that blends Medicare and private pay or Medicaid payments) community-based long-term care (LTC) program that provides a comprehensive array of primary, acute and LTC services for frail elders who are eligible for a skilled nursing facility level of care. PACE was authorized as a Medicaid state plan option by the Balanced Budget Act of 1997; before that time, it existed as a waiver program.

ⁱⁱⁱ Categorical eligibility refers to persons who are eligible for Medicaid because they fall into a specific group based on age and low-income status. In this case, it would include low-income elders (age 65 and older) or low-income individuals with permanent and significant disabilities.

^{iv} Home and Community-based Services (HCBS) waivers are an array of long-term care supportive services funded by Medicaid and provided in a community setting with the goal of meeting the health, functional and behavioral health needs of low-income elders and individuals with disabilities who otherwise would be eligible for placement in a facility such as a nursing home.

OLDER AMERICANS ACT AND OLDER COLORADANS ACT-FUNDED SERVICES

The Colorado State Unit on Aging (SUA) provides funding and policy direction to maintain the independence of older adults through providing an array of services funded by the Older Americans Act (OAA) and Older Coloradans Act (OCA). Program service areas include: caregiver training and support (respite), long-term care ombudsman, money management, in-home and congregate nutrition services, senior employment, and other supportive services such as transportation and home modifications.

The SUA works closely with 16 Area Agencies on Aging (AAA) to deliver services to communities throughout Colorado. Although the SUA is the single state agency that receives and distributes federal OAA dollars to local AAAs, there is very little state involvement in how OAA dollars are distributed at the local level beyond the guidance provided by the federal Administration on Aging (AoA).

Knowing how to gain access to the services offered by the LTC system can be difficult. The most common route into Colorado's formal long-term care system is through one of 25 single entry points (SEPs) geographically dispersed around the state. In the broadest sense, SEPs provide a range of services that include information and referral assistance, initial eligibility screening, nursing home preadmission screening, assessment of functional capacity and service needs, care planning, service authorization, monitoring and periodic reassessments for Medicaid-eligible LTC individuals. SEPs are responsible for determining functional eligibility for Medicaid LTC services including community-based LTC programs and nursing home care. In addition, SEPs provide care planning and case management for individuals enrolled in these programs, which include Medicaid home and community-based waivers (see Cost of Services section for more information).²⁴

Adult Resources for Care and Help (ARCH) is Colorado's version of the national Aging and Disability Resource Center program (ADRC), which is funded by the Administration on Aging and CMS. ARCH does not aim to create new services but rather to serve as a single entry point for a broad range of long-term care services that are not dependent on Medicaid eligibility. The ARCH program strives to provide assistance to all individuals by facilitating their navigation through the entire long-term care continuum.

Table 4. SEPs and the ARCH alternative: Entry to Colorado’s long-term care service system

	Single Entry Points (SEPs)	Adult Resources for Care and Help (ARCH)
Goal	Enable Medicaid-eligible consumers to gain access to long-term supportive services through one agency.	Enable consumers to gain access to long-term and supportive services through one agency.
Audience	Implemented in 1993, the program offers services for the elderly and people with disabilities who are eligible for Medicaid LTC services.	Implemented in 2005 as a pilot program, the program is available to all adults age 60 and older and those 18 years and older with a disability.
Funding	The statewide network of SEPs is funded as a Medicaid administrative function by the Department of Health Care Policy and Financing with matching federal funds.	ARCH is a collaborative effort of the federal Administration on Aging and Centers for Medicare and Medicaid Services. Beginning in 2003, three-year federal grants were offered to states to develop Aging and Disability Resource Centers (ADRC); in 2005, Colorado became a grantee and created ARCH. In addition to the grant, pilot sites are using local funds, Older Americans Act funding and state senior services funds.
Locations	Local AAAs serve all of Colorado’s 64 counties through 25 geographic regional offices.	Larimer, Mesa, Pueblo and El Paso counties
Referrals	Work as a referral service more than providing direct services; do not include private services in their referral networks.	Provide referrals for both public <i>and</i> private services regardless of the consumer’s income level.

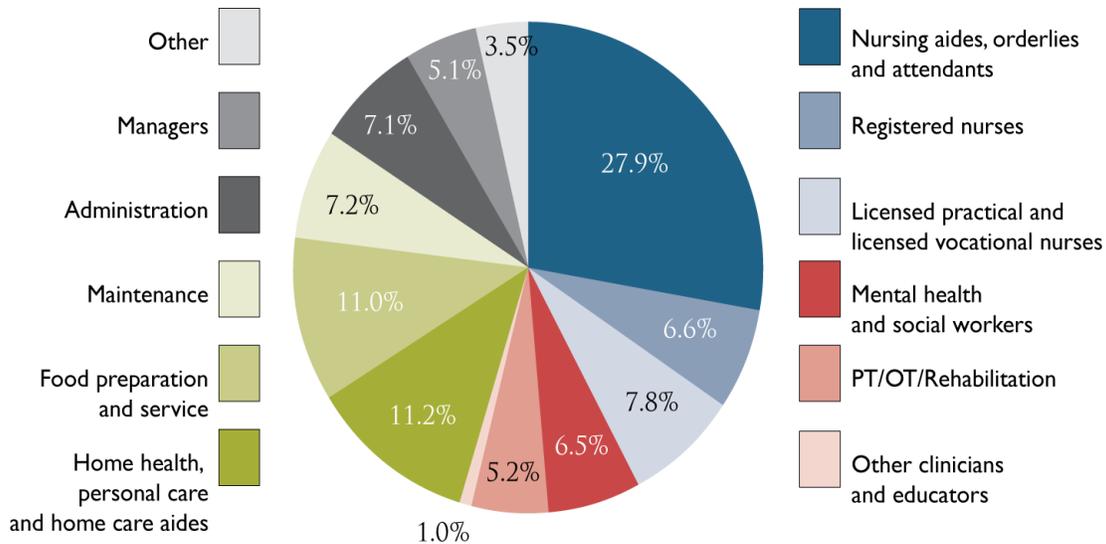
Recently enacted federal reform legislation, the *Patient Protection and Affordable Care Act*, provides grants to states to implement specific strategies for re-balancing systems of long-term care to make them more consumer-responsive and focused on home and community-based services. In September 2010, the Colorado SUA was awarded three grants to improve access to community-based LTC services.

LTSS WORKFORCE

Colorado’s formal LTC workforce is diverse and involves many occupational groups. Approximately 42 percent of the long-term care workforce is composed of nurses including registered nurses (RNs), licensed practical nurses (LPNs) and certified nurse aides (CNAs). Other clinicians such as physical therapists and social workers account for an additional 13 percent of the workforce, while home health

aides represent just over 11 percent. The remainder is comprised of occupations such as food service workers, janitors, managers and administrators (Graph 5).

Graph 5. Staffing patterns for nursing homes and residential care facilities, Colorado, 2009



SOURCE: LMI Gateway, Colorado Department of Labor and Employment

Almost 40 percent of the formal LTC workforce is comprised of workers with a minimum level of formal training. These hands-on caregivers include CNAs, personal care attendants and home health aides. Personal care workers provide assistance with activities of daily living and instrumental activities of daily living, including help with transferring from bed to wheelchair, feeding and grooming, meal preparation and household chores.

For additional information about the responsibilities and training requirements of the professions outlined in Graph 5, see Appendix B.

A well-documented shortage of long-term care providers exists; high turnover rates, large numbers of job vacancies and difficulties in recruiting new workers challenge the industry. In addition, the demographics of the population are shifting—those needing LTC will be more ethnically diverse, better educated and wealthier than in the past. The effects of an aging population are likely to compound the effects of the projected shortfall of long-term care workers. Immigrants are an important source of the LTC workforce, particularly home-based caregiving as well as in nursing homes.^{25, 26}

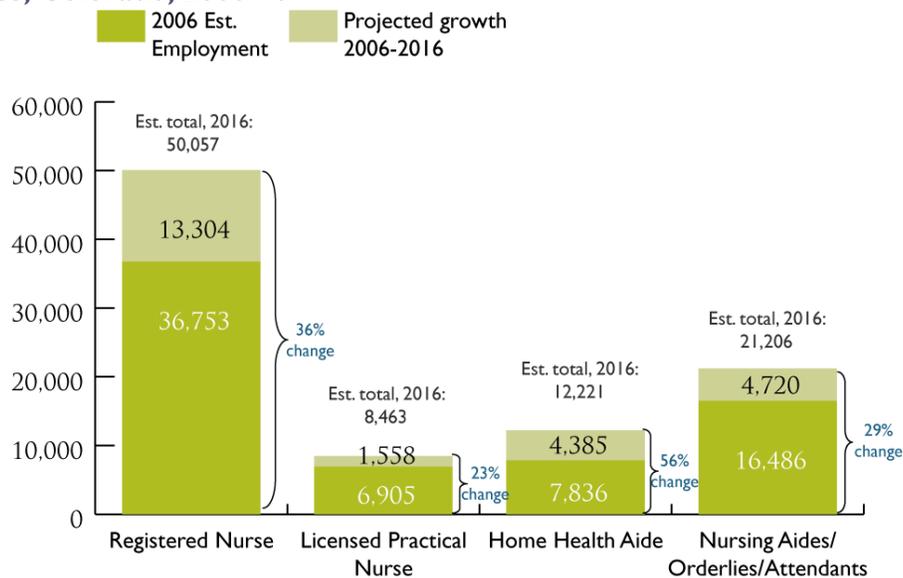
Demand for an LTC workforce

As discussed earlier in this paper, the number of individuals with Alzheimer’s in the United States is expected to increase substantially over the next few decades. As a result, the long-term care workforce will need to expand to meet their needs. The National Academy of Science estimates that an additional 3.5 million formal LTC caregivers will be required by 2030 just to maintain current levels of staffing in LTC facilities.

According to the U.S. Bureau of Labor Statistics, the nationwide demand for workers in nursing and residential care facilities is expected to increase by 21 percent between 2008 and 2018. Positions in home health care are expected to increase by 46 percent during this time period.²⁷

This growth in demand for hands-on caregivers is expected to outpace the growth in demand for professional nurses. Employment of RNs and LPNs in home health settings is projected to grow by 33 percent between 2008 and 2018, while the demand for personal care attendants and home health aides is expected to grow by 54 percent and 63 percent respectively.

Graph 6. Projected growth by type of professional and paraprofessional nursing workforce, Colorado, 2006-16



SOURCE: Colorado Department of Labor and Employment, LMI Gateway²⁸

Clinical experience and classroom instruction in meeting the needs of individuals with Alzheimer’s disease

As mentioned previously, nurses in Colorado are not required to receive Alzheimer’s-specific training prior to licensure. As a result, only half of Colorado’s LPNs and RNs employed in an LTC setting reported that their academic training prepared them to care for people with dementia and other mental impairments.

Table 5. Percent of Colorado licensed practical nurses (LPNs) who rated their nursing instruction as Adequate or Most Adequate by topic of instruction, 2007-08

Topics	LPNs employed in LTC setting	LPNs employed in all other settings
Classroom instruction topics		
Caring for the elderly	65.2%	72.7%
Caring for persons with dementia and other mental impairments	47.3%	49.6%
Clinical instruction topics		
Caring for the elderly	67.9%	78.9%
Caring for persons with dementia and other mental impairments	49.6%	56.2%

SOURCE: 2007-08 Colorado Licensed Practical Nurse Workforce Survey, Colorado Health Institute

Table 6. Percent of Colorado registered nurses who reported their nursing instruction as Good or Excellent by topic of instruction, 2008

Topics	RNs employed in LTC setting	RNs employed in all other settings
Classroom instruction topics		
Caring for the elderly	55.4%	63.0%
Caring for persons with dementia and other mental impairments	52.9%	50.4%
Clinical instruction topics		
Clinical rotation in a nursing home	37.5%	40.3%
Clinical rotation in a psych/behavioral health setting	67.5%	69.1%

SOURCE: 2008 Colorado Registered Nurse Workforce Survey, Colorado Health Institute

The Colorado Health Institute’s (CHI) 2007-08 Colorado LPN Workforce Survey also asked about interest in further on-the-job training in certain areas. LPNs employed in LTC settings were more likely to report being interested in additional on-the-job training resulting in a certificate of program completion than LPNs in other work settings—79 percent expressed interest in additional training in geriatrics and 77 percent in training about Alzheimer’s disease and/or other types of mental disorders. In contrast, slightly more than half of LPNs working in other settings reported an interest in additional training in geriatrics and Alzheimer’s disease.

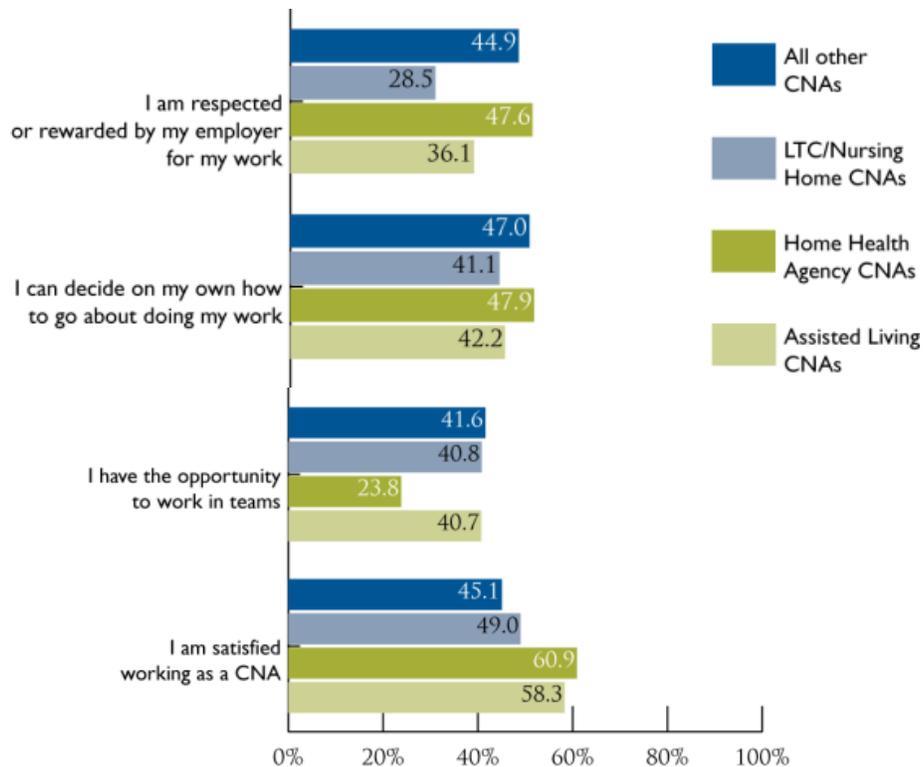
Dissatisfaction and turnover within long-term care workforce

Direct care jobs are characterized by low wages, limited benefits and challenging working conditions.²⁹ As a result, high turnover rates among direct care workers are a serious workforce issue for long-term care facilities, which has led to a substantial body of literature on the subject.^{30, 31} National estimates of turnover in the LTC workforce vary widely. Most studies estimate turnover rates between 40 and 100 percent, though these figures vary by region and type of facility.^{32, 33, 34} Numerous studies suggest that high turnover negatively affects the quality of care—both the continuity of care and the personal relationships that develop between staff and patients suffer when turnover is high.³⁵ In addition, high

rates of staff turnover are costly for facilities because they add to recruitment and training costs. It is estimated that the direct cost of replacing a frontline LTC worker is *at least* \$2,500.³⁶

According to CHI's 2006 Colorado Certified Nurse Aide Workforce Survey, when asked how many years they planned to continue working as a CNA, 24 percent reported plans to leave the profession within five years. The following graph displays various dimensions of CNA job satisfaction.

Graph 7. Percent of Colorado CNAs reporting a high level of agreement with statements about their primary workplace, 2006



NOTE: "All other" includes hospital, private home, hospice, medical practice office or clinic, and other categories

SOURCE: 2006 Colorado Certified Nurse Aide Workforce Survey, Colorado Health Institute

As shown in Graph 7, CNAs working in long-term care facilities were less likely to report feeling respected or rewarded by their employer than those working in non-LTC settings. Only 29 percent of CNAs in LTC work settings reported feeling respected by their employer. CNA respondents working in home health agencies reported a higher level of overall job satisfaction than all other CNAs.

LPNs in LTC work settings were also much more likely to report plans to leave their current job within the next year when compared to all other employment settings. In the 2007-08 survey, 28 percent of LPNs working in an LTC setting reported that they planned to quit their current nursing job within the next 12 months. Only 16 percent of LPNs working in other settings reported that they planned to leave within a year.

Asked about the factors that influenced their decision to leave their job, LPNs planning to leave within 12 months cited insufficient wages (78%), high levels of stress (77%) and not feeling respected in their workplace (56%) as the top reasons. Long-term care LPNs were more likely than all other LPNs to want to leave their job because of problems with workplace safety, high levels of stress, long hours, insufficient wages and a desire to pursue more education.

RESPIRE FOR FAMILY CAREGIVERS

Respite care provides family caregivers intermittent time for rest and relief from caregiving responsibilities as well as giving the care receiver a chance to meet new people and have new experiences. Respite can be delivered in a variety of ways, including in-home respite care, adult day centers and informal respite care and is most often utilized occasionally or on a regular intermittent basis depending on the needs of the caregiver. As mentioned earlier in the report, Colorado has 67 Medicaid-certified adult day programs. Many other organizations around the state provide varying types of respite, but are not regulated by the state.

DIAGNOSTIC SERVICES

Diagnosing Alzheimer's disease in the early stages can be difficult; however, an early diagnosis is beneficial for many reasons.³⁷ Even though the underlying processes of Alzheimer's disease cannot be changed, starting treatment with an early diagnosis can preserve function for months to years. An early diagnosis also helps individuals and the families make plans for the future, including financial and legal matters, living situations and developing support networks. An October 2010 report from the International Working Group for New Research Criteria for the Diagnosis of AD calls for diagnosing Alzheimer's a decade before the clinical memory symptoms appear by using biomarker tests and scans that detect biochemical signals that the disease process is happening. Preventive medications need to be started once these tests are positive in order to prevent or delay the onset of the clinical symptoms of cognitive impairment. These tests are not cheap and they will need to be employed on a very large segment of the population under age 65. Although the cost of this type of widespread testing would be high, the expectation is that there would be tremendous savings by preventing or delaying the need for formal long-term care.³⁸

In Colorado, the majority of diagnostic services are located in the metropolitan areas of the state. In Metro Denver, for example, specialty clinics provide diagnostic services in addition to internists, neurologists and geriatricians who are trained to provide an evaluation and diagnosis. Other cities in the state, such as Colorado Springs, Fort Collins, Greeley, Pueblo and Grand Junction, also have diagnostic services. Unfortunately, many primary physicians in small towns are not trained to diagnose Alzheimer's disease, meaning these services are lacking in most rural areas of the state.

PALLIATIVE AND END-OF-LIFE CARE

Hospice provides palliative services to terminally ill individuals and support for their caregivers and families. These services do not cure illness but rather provide the greatest degree of relief from symptoms and maximize quality of life. In Colorado, hospice programs are required to provide physician and nursing care, personal care and therapy, pastoral and emotional/psychological counseling as established by a plan of care. Hospice can be delivered both in a formal setting, such as a nursing home or residential care facility and in the home. The Colorado Department of Public Health and Environment

conducts surveys to ensure compliance with state and federal certification and licensing standards. In 2006, there were about 43 hospice programs operating in Colorado with most certified to provide services for Medicare-eligible persons.³⁹

ALZHEIMER'S DISEASE RESEARCH (BASIC SCIENCE AND SOCIAL/BEHAVIORAL)

Although Colorado does not provide financial support for Alzheimer's disease research at any of the state's institutions of higher education, the Department of Neurology within the University of Colorado School of Medicine is conducting a number of research investigations about the biological processes associated with Alzheimer's disease. The Neurology Department recently received a private bequest of more than \$1.1 million to enhance research related to Alzheimer's disease. With this money, the department plans to hire a faculty researcher whose focus will be on translating basic Alzheimer's disease research into clinical applications. Colorado State University (CSU) researchers also conduct basic cellular and molecular biology research on dementia processes. CSU has also had \$3.3 million in federal funding from 2002 to 2012 to provide and evaluate AD caregiver training and interventions throughout the state, in collaboration with the Alzheimer's Association Colorado Chapter and the state's Division of Aging and Adult Services.

REGIONAL AVAILABILITY OF RESOURCES

Although Colorado state agencies and community-based organizations within the state have tried to provide comprehensive services to people affected by Alzheimer's disease and other dementia, many gaps still exist. A large gap exists in the services available for individuals living in rural areas. In Colorado, about 15 percent of individuals live in rural communities.⁴⁰ Many rural populations are geographically isolated, with some counties in Colorado averaging only four individuals per square mile.⁴¹ Because rural populations are much more dispersed than urban, they provide a special challenge to disseminate information and direct services. Further, because of the low population density in rural areas, it is often not cost effective to locate services in rural communities.⁴²

Colorado's 2004-07 State Plan on Aging identified three areas in which the needs and resources for individuals in rural areas differ from those in urban areas: medical care, medical-related transportation and nutrition-related programs. Rural populations tend to experience higher rates of chronic conditions, are uninsured for longer periods of time and have higher health care expenditures. Access to medical care in rural communities is more limited than in urban areas of the state. Lack of public transportation exacerbates this problem as individuals have few, if any, resources available to seek available medical care in more urban areas of the state. Further, nutrition programs such as congregate meals and Meals on Wheels often do not reach individuals living in isolated rural settings.⁴³

The following maps display the current inventory of LTC facilities around the state and in the major metropolitan areas (2009) in the context of projected increases in the 65+ population for each county in Colorado from 2008 through 2020. The metropolitan areas have significantly more services and facilities than the rural areas. Of particular note is Eagle County which will have an increase of more than 5,000 people ages 65 and older, yet has only one home health agency and no other facilities or long-term support programs. It should be noted that this map is representative of the availability of LTSS as of 2009 and that it is a dynamic industry that will undoubtedly grow as the Colorado population ages.



Long-term care services and projected change in population ages 65 and over, 2008-20



- Services**
- Assisted living residence-Medicaid certified
 - Assisted living residence-private pay
 - ◆ Nursing home-Medicare certified
 - ◆ Nursing home-Medicaid certified
 - ◆ Nursing home-Medicare/Medicaid certified
 - ◆ Nursing home-private pay only
 - ★ *HCBS: Adult day program/brain injury-Medicaid certified
 - ★ HCBS: Adult day program-Medicaid certified
 - ★ HCBS: In-home support services-Medicaid certified
 - ★ HCBS: Personal care homemaker/brain injury-Medicaid certified
 - ★ HCBS: Personal care homemaker-Medicaid certified
 - Home health agency-Medicare/Medicaid certified
- Population change, 65+, 2008-20**
- Lightest green: ≤1,000
 - Light green: 1,001-2,500
 - Medium green: 2,501-5,000
 - Dark green: 5,001-7,500
 - Dark blue: ≥7,501

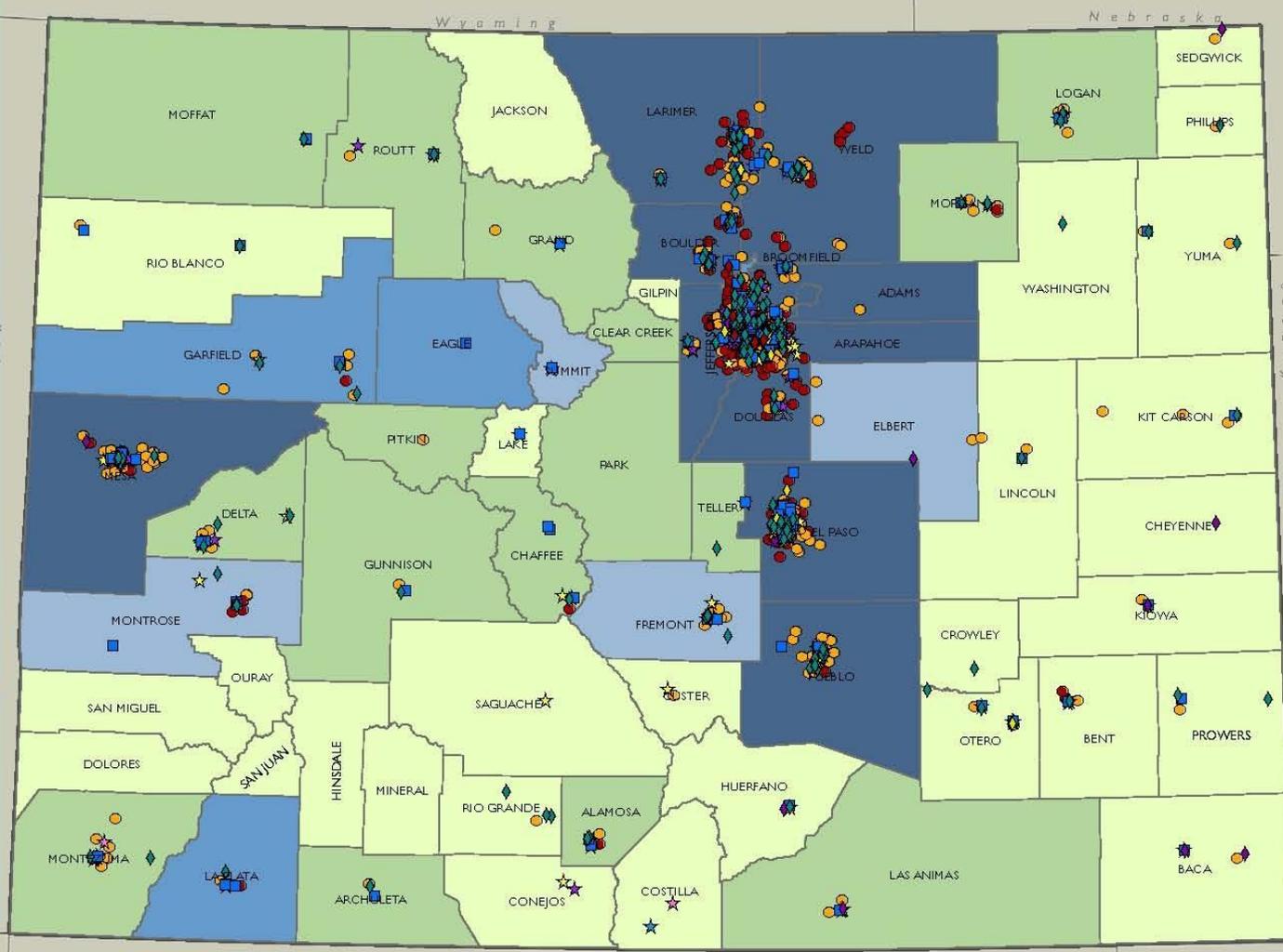
*Home and Community-based Services

Demographic data downloaded from the Colorado State Demography Office Web site on May 6, 2009.
www.dola.state.co.us/dlg/demo/g/index.html

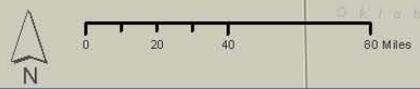
Long-term care facilities and services downloaded from the Colorado Department of Public Health and Environment Web site on June 23, 2009.
www.cdphs.state.co.us/hfi/

Due to facility overlap, location of points was spatially adjusted.

Map prepared by the Colorado Health Institute
 1576 Sherman St., Ste. 300
 Denver, CO 80203-1728
 303.831.4200
www.coloradohealthinstitute.org



Map created July 1, 2009





Long-term care services and projected change in population ages 65 and over, 2008-20



Services

- Assisted living residence-Medicaid certified
- Assisted living residence-private pay
- ◆ Nursing home-Medicare certified
- ◆ Nursing home-Medicaid certified
- ◆ Nursing home-Medicare/Medicaid certified
- ◆ Nursing home-private pay only
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- ★ HCBS: In-home support services - Medicaid certified
- ★ HCBS: Personal care homemaker/brain injury-Medicaid certified
- ★ HCBS: Personal care homemaker - Medicaid certified
- Home health agency-Medicare/Medicaid certified

Population change, 65+, 2008-20

- ≤1,000
- 1,001-2,500
- 2,501-5,000
- 5,001-7,500
- ≥7,501

— Major highway

*Home and community-based services

Demographic data downloaded from the Colorado State Demography Office Web site on May 6, 2009.

www.doh.state.co.us/dlg/demog/index.html

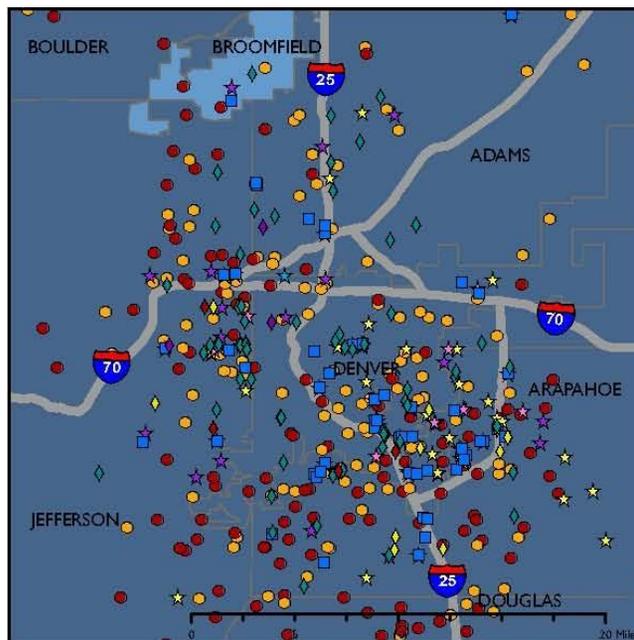
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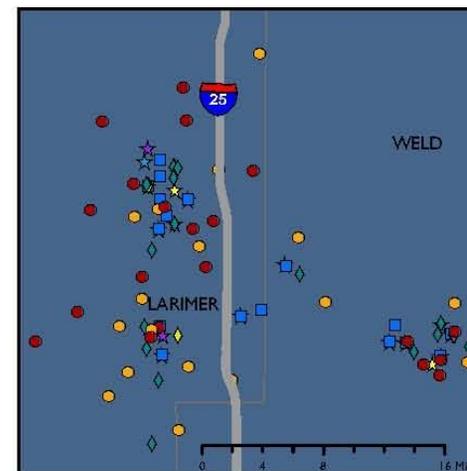
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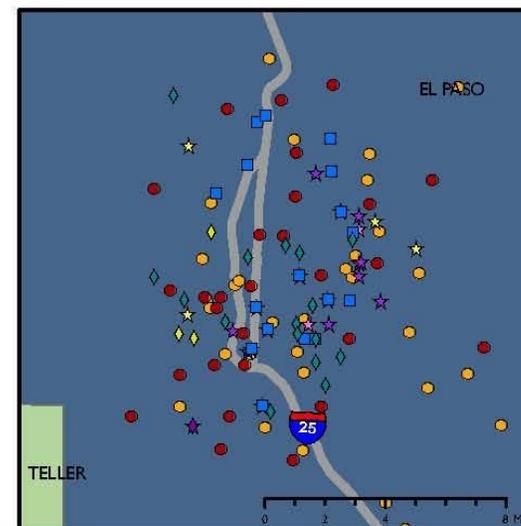
Metropolitan Denver



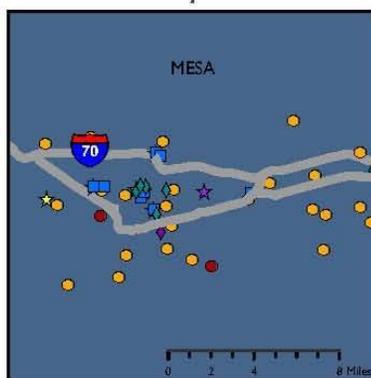
Larimer/Weld Counties



El Paso/Teller Counties



Mesa County



Maps created July 1, 2009

Chapter 3: Financing Long-term Support Services for Alzheimer’s Patients

Due to the nature of the disease, individuals with Alzheimer’s and related dementia are high users of medical and long-term support services. A variety of public and private sources finance this care (see Table 7). Total payments from all sources are three times higher for individuals with Alzheimer’s disease and related dementia than for other older adults on Medicare.

Table 7. Average per-person payment for health and LTC services, Medicare beneficiaries ages 65+ with and without AD or other dementia, 2004

	Beneficiaries with no AD or other dementia	Beneficiaries with AD or other dementia
Total Payments*	\$10,603	\$33,007
Payments from specified sources		
Medicare	\$5,272	\$15,145
Medicaid	\$718	\$6,605
Private insurance	\$1,466	\$1,847
Other payers	\$211	\$519
HMO	\$704	\$410
Out-of-pocket	\$1,916	\$2,464
Uncompensated	\$201	\$261

NOTE: Created from Alzheimer’s Association. *Characteristics, Costs and health Service Use for Medicare Beneficiaries with a Dementia Diagnosis: Report 1: Medicare Current Beneficiary Survey, 2009* [78]

*Payments by source do not equal total payments exactly due to the effect of population weighting.

PUBLICLY FINANCED CARE

Medicare

Medicare pays only for *medically* necessary skilled nursing facility and home health care. Medicare does not pay for custodial or personal care which includes assisting individuals with functional impairments in their activities of daily living. In 2004, overall Medicare reimbursements were three times more for beneficiaries with Alzheimer’s disease and related dementia than beneficiaries without dementia. The majority of Medicare spending for beneficiaries with Alzheimer’s disease was hospitalizations, followed by medical providers (Table 8).

Table 8. Average per-person payments for health care services, Medicare beneficiaries ages 65+ with or without AD and other dementia, 2004

Healthcare service	Average per-person payment for those with no AD or other dementia	Average per-person payment for those with AD or other dementia
Hospital	\$2,748	\$7,663
Medical provider *	\$3,097	\$4,355
Skilled nursing facility	\$333	\$3,030
Home health care	\$282	\$1,256
Prescription medications†	\$1,728	\$2,509

NOTE: Created from Alzheimer’s Association. *Characteristics, Costs and health Service Use for Medicare Beneficiaries with a Dementia Diagnosis: Report 1: Medicare Current Beneficiary Survey, 2009* [78].

*“Medical provider” includes physician, other medical provider, laboratory services, and medical equipment and supplies.

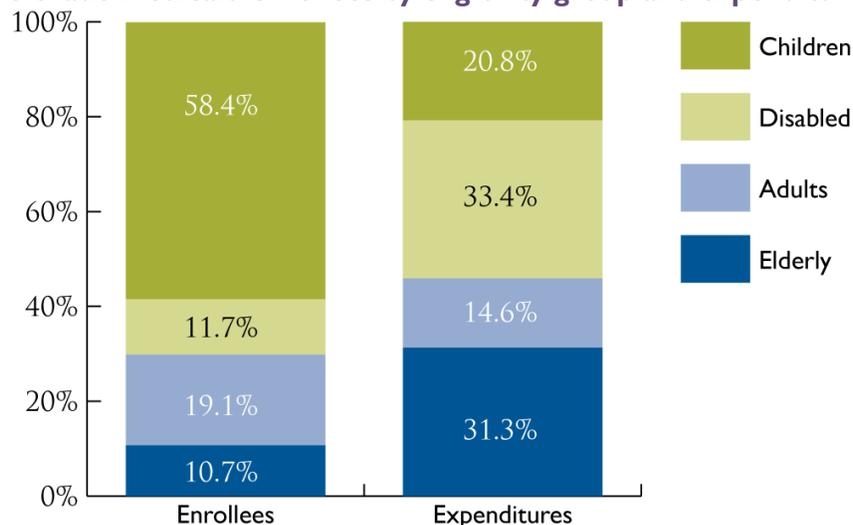
† Payment for prescription drugs is only available for people living in the community, not in a nursing home or assisted-living facility.

Medicaid

Medicaid pays for institutional and community-based LTC for individuals with limited incomes (up to 219% of the federal poverty level [FPL] or \$2,022 per month in 2009 with limited assets. Assets are limited to \$2,000 for an individual, \$4,000 for a married couple or \$109,560 if one member of the couple is applying for long-term care and the other spouse is not and is not institutionalized. Each state is responsible for administrating its own Medicaid program using a combination of federal and state dollars. Colorado’s Medicaid program serves low-income populations across the lifespan, from newborns to old age.

Graph 8 shows the populations served by Colorado Medicaid and the percentage of overall Medicaid expenditures that each eligibility group consumes. Medicaid financing is by far the largest single source of funding for LTC and when combined with acute care for people with disabilities and the elderly accounts for more than half of all Medicaid spending in Colorado.

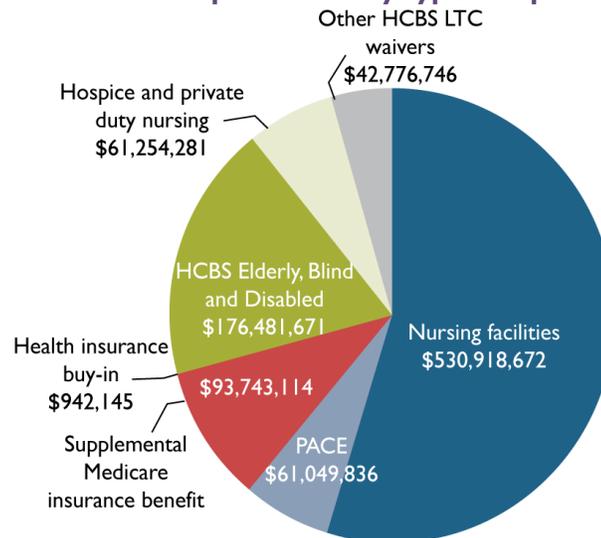
Graph 8. Colorado Medicaid enrollees by eligibility group and expenditures, FY 2009-10



SOURCE: Colorado Department of Health Care Policy and Financing, FY 2010-11 Budget Request

The Colorado Medicaid program spent more than \$863 million on LTC in FY2007-08, although this amount was considerably lower than the national average, ranking Colorado 46th in the country for overall LTC Medicaid expenditures per capita.⁴⁴ Graph 9 displays the amount and the proportion that Colorado spends on LTC by type of program. A majority (56%) of Medicaid LTC spending in Colorado is for nursing home care.

Graph 9. Colorado Medicaid LTC expenditures by type and place of service, FY 2008-09



SOURCE: Colorado Department of Health Care Policy and Financing, FY 2010-11 Budget Request, Exhibit H⁴⁵

In Colorado, Medicaid LTC enrollees can receive care in a nursing home or through a home and community-based service (HCBS) waiver. HCBS waivers provide an array of LTC supportive services in a community setting with the goal of meeting the health, functional and behavioral health needs of low-income elders and individuals with disabilities who otherwise would be eligible for placement in a nursing home. In Colorado, the number of individuals enrolled in Medicaid waivers has increased over the past three years from 26,746 in FY 2005-06 to 30,738 in FY 2008-2009. Over that same period, the number of individuals enrolled in nursing facilities dropped slightly from 14,299 to 13,636.⁴⁶

The most heavily subscribed HCBS waiver is the elderly, blind and disabled (EBD) waiver. In FY 2006-07 in Colorado, 13,070 full-time enrollee equivalents were on the HCBS-EBD waiver compared to 9,681 full-time equivalent enrollees (FTEs) in a nursing facility. Medicaid recipients residing in a nursing home incur much higher costs than those on an HCBS-EBD waiver. In FY 2006-07, the Medicaid costs for an FTE enrollee⁵ in a nursing home was \$49,408, while the cost per FTE enrollee on an HCBS-EBD waiver was \$9,221 (waivered costs per FTE enrollee do not include pharmaceuticals and skilled nursing services as is the case in nursing home care; these costs for waiver enrollees are incurred in the acute care services budget).⁴⁷

⁵ Full-time equivalent (FTE) enrollee refers to the equivalent of an enrollee in the program for 365 days. For example, two enrollees, one of whom was in the program for 300 days and the other of whom was in the program for 65 days, would be counted as one full-time enrollee equivalent.

Individuals who qualify for Medicaid have out-of-pocket costs as well. Medicaid-reimbursed nursing home residents are required to contribute all of their income, with the exception of a small personal needs allowance, toward the cost of their nursing home. On average, Medicaid nursing home residents contribute 20 percent to the cost of their care.⁴⁸ In Colorado, they contribute slightly less than the national average or about 17 percent of the cost of their care.⁴⁹

OUT-OF-POCKET COSTS

Because Medicaid and Medicare do not cover the full costs of long-term care, many people choose to buy LTC insurance or pay the costs of care out of pocket. In 2006, private health and long-term care insurance accounted for only about 9 percent of long-term care spending nationally.

Colorado participates in the Long-Term Care Partnership program, which offers LTC insurance through a public/private arrangement between long-term care insurers, Colorado's Medicaid program, the Division of Insurance, the Department of Human Services and individuals. The insurance is designed to help Coloradans pay for long-term care without depleting all of their assets.

Out-of-pocket costs incurred by individuals and families are high and include Medicare and other health insurance premiums, deductibles and copayments and long-term care services that are not covered by Medicare, Medicaid or other sources. In 2004, Medicare beneficiaries aged 65 and older with Alzheimer's disease and related dementia had average out-of-pocket costs per person of \$2,464; on average, nursing home and ACF residents paid out-of-pocket costs of \$16,689 per person.⁵⁰

The federal *Patient Protection and Affordable Care Act* contains a provision to establish an employer-based, income tax-funded community-based LTC insurance benefit. It is designed to provide individuals who pay into the program a flexible cash payment to purchase supportive services based on level of need. Workers must pay into the program for at least five years before becoming eligible for the benefit.

ECONOMIC VALUE OF UNPAID INFORMAL CAREGIVING

Approximately three-quarters of adults who need LTC receive it from informal caregivers, such as friends and family members, while an additional 14 percent receive a combination of informal and formal caregiving. According to the U.S. Department of Health and Human Services, the demand for unpaid informal caregivers is expected to outpace the demand for formal services. Between 2000 and 2050, the demand for formal services is expected to increase from 1.8 million to 3.5 million; in contrast, the demand for informal caregivers is expected to grow from 21.6 million in 2000 to 40.1 million by 2050.⁵¹

In Colorado, 161,600 unpaid caregivers provided more than 184 million hours of personal care and assistance to individuals with Alzheimer's disease and related dementia in 2009. The economic value of each hour of family caregiving has been estimated to be \$11.50 with a total economic value placed on informal caregiving for individuals with Alzheimer's disease and related dementia in Colorado at approximately \$1.9 billion annually.⁵²

Sixty percent of informal caregivers for Alzheimer's patients are women.^{53, 54} The average age of these caregivers is 51 years. Approximately one-third of informal caregivers have children under the age of 18 living at home—a group known as the “sandwich generation” for their dual caregiving responsibilities.⁵⁵

Chapter 4: Quality of Life and Quality of Care for People with Alzheimer's Disease

MEASURING AND MONITORING QUALITY OF CARE

Quality is an important dimension of the care provided to individuals with Alzheimer's disease. Quality measures are generally thought about in two ways. The medical perspective takes into account the medical needs of an individual and the quality of care they receive to meet those needs. On the other hand, quality of life is person-centered, taking into account not only medical but also social and personal needs embedded in individual preferences. To provide quality care in a quality-of-life context, family caregivers and facility staff need specific training in the symptoms and behaviors associated with Alzheimer's and related dementia.

The state's role in regulating quality of care is primarily from a medical and public safety perspective, although performance standards have been implemented by the Colorado Department of Public Health and Environment (CDPHE) which include quality-of-life metrics. CDPHE's Standards for Hospitals and Health Facilities are available on the department's website and include performance standards for hospitals, nursing homes, hospice, assisted-living facilities and home care agencies.⁵⁶

CDPHE's regulatory tools include facility inspections, responding to complaints and occurrence reporting such as unexplained deaths or missing persons. Nursing homes are inspected once a year on average as required by the federal government, and home care agencies are inspected about once every three years. Very few of CDPHE's quality tools are specific to individuals with Alzheimer's disease or related dementia.

The Alzheimer's Association is currently conducting a Quality of Care Campaign with the dual goals of enhancing quality of life for individuals with dementia and improving the quality of care they receive. Quality care for people with dementia includes educating their caregivers, including consistency in the caregiving experience. The Association has released evidence-based dementia care practice recommendations in four phases, three for assisted-living facilities and nursing homes and one for home-based care. Colorado caregivers have several opportunities to attend training programs, including an annual symposium, classroom and online training, and the Alzheimer's Learning Institute.⁵⁷

Although the Association offers and promotes its training programs, there is no requirement that paid caregivers receive dementia-specific training. Personal care attendants are required to receive training prior to employment, but it is minimal. Although both CNAs and LPNs must complete a training program approved by the Board of Nursing within the Colorado Department of Regulatory Agencies, there is no required course content in working with individuals with Alzheimer's and related dementia, nor does the Colorado Board of Nursing require dementia-specific course content be offered in RN education programs.

While Colorado's licensing boards do not require dementia-specific training for most of the long-term care workforce, a few programs in the state promote education in gerontology and geriatrics. Several national boards offer certification in gerontology or geriatrics for nursing and the allied health

professions. The University of Colorado School of Medicine Center on Aging offers general medicine residents a geriatric rotation, medical students are offered geriatric electives, and there are limited geriatric fellowships. In addition, geriatric training is available for pharmacy, dental and nurse practitioner students.⁵⁸

The University of Colorado at Colorado Springs houses a Gerontology Center, offering a minor in gerontology, a PhD program with an emphasis in Geropsychology as well as a Professional Advancement Certificate in Gerontology for community residents who are interested in specializing in aging. The Center also provides community-based training including in-service education to staff in LTC facilities, technical assistance, workshops, co-sponsorship of an annual geriatric health conference and assistance with applied research projects.⁵⁹ Colorado State University offers similar training and a certificate in gerontology through the Center on Aging's Gerontology Interdisciplinary Studies Program.

Discussions about quality of care for individuals with Alzheimer's disease should include a discussion of caregiver well-being as well.⁶⁰ Those who care for individuals with Alzheimer's disease are significantly more likely to experience depression, stress, deterioration of physical health and other negative psychological effects.^{61, 62}

Two Colorado programs have been found to be effective at mitigating caregiver burden—the *National Family Caregiver Support Program (NFCSP)* supported by the State Unit on Aging and the *Savvy Caregiver* program administered by the Colorado Chapter of the Alzheimer's Association.⁶³ The Chapter regularly provides equivalent training programs for all stages of dementia.

NFCSP provides a range of services for caregivers that include respite care and caregiver training. For FY2008-09, NFCSP served approximately 5,000 caregivers in Colorado. The *Savvy Caregiver* program is a 12-hour training module that offers both information and skill-building in caring for individuals with Alzheimer's disease. The program is offered at least 30 times annually in Denver and among the Association's regional offices by the Colorado Chapter of the Alzheimer's Association.

QUALITY-OF-CARE METRICS

As discussed above, quality of care encompasses two dimensions of quality—medical/biological and person-centered quality of life. For each, metrics have been developed and are widely used by the Centers for Medicare and Medicaid Services and the long-term care industry, developed through partnerships with trade associations and universities.

Nursing home performance measures endorsed by the National Quality Forum include assistance with activities of daily living, pain management, use of physical restraints, the prevalence of urinary tract infections, worsening of depression and anxiety, risk of acquiring pressure sores, rates of pneumococcal vaccinations and post-acute hospitalization re-admission rates.⁶⁴ The *Annals of Internal Medicine* conducted a literature review of quality indicators for Alzheimer's disease; 14 were judged to be valid and reliable by an expert panel.

In the alternative, Wisconsin has developed quality-of-life metrics that go beyond the quality of medical care and facility safety to those that measure person-centered quality of life, including personalized care

planning involving the consumer and his/her family, ability to engage in preferred activities and many more metrics that are monitored over time. All of the Wisconsin measures are stated in the first person and therefore are consumer-focused. There are five outcomes, each with observable measures. For example, the first outcome is: “As a person with dementia, I have the best possible physical well being.” Metrics for this outcome include, “I am well hydrated,” “I am clean” and “I am physically active.” A person-centered outcome is: “As a person with dementia, I have hope because my future is valued and supported.”⁶⁵

Chapter 5: Public Safety and Public Awareness

Wandering is one of the most significant risks involving people with Alzheimer's disease—nearly 60 percent wander at some point during the course of their illness. Approximately half of wanderings lead to injury if the individual is not found within 24 hours. Several programs have been designed to reduce the risk of wandering and ensure a safe return if wandering occurs.

The ability of law enforcement to respond swiftly to reported cases of wandering in Colorado was widely expanded in 2007 when the state implemented a coordinated response system similar to the Amber Alert for missing children. The program was subsequently expanded to include missing persons with developmental disabilities. Like Amber Alert, information is sent to designated media outlets including radio and television stations which issue an alert at designated intervals. For an alert to be issued, caretakers must provide evidence of the impaired mental condition of the missing person to law enforcement officers.

Two programs that mitigate the risks associated with wandering include *MedicAlert + Safe Return* and *Comfort Zone*. *MedicAlert + Safe Return* is a national emergency response service for individuals with Alzheimer's disease or related dementia. Individuals in the program are issued a personalized identification bracelet or medallion. Family members can report a missing person to the hotline and initiate a response from local Alzheimer's associations and law enforcement agencies. *Comfort Zone* allows families and caregivers to set up a designated perimeter with family members alerted if the enrollee leaves this designated area. Similarly, *Colorado Life Track* uses radio signals to locate a missing person wearing a locator device.

Another safety risk for individuals with Alzheimer's disease is diminished ability to drive. Currently, the Colorado DMV has the authority to cancel, deny or deny reissuance of a license for several reasons, including the inability to operate a motor vehicle because of physical or mental incompetence.⁶⁶ The written medical opinion of a licensed physician, physician's assistant or optometrist may be used for the renewal, suspension, revocation or cancellation of drivers' licenses. At the present time, Colorado does not have a streamlined process for doctors to report a medical opinion to the DMV.

Chapter 6: Identified Gaps and Policy Recommendations

Below is a discussion of identified gaps in supportive care and timely response with a set of recommendations put forth by the CACC as a result of its study and deliberation about the many issues associated with individuals and families living with Alzheimer's disease. Each recommendation identifies the issue, provides a strategy to address it and specifies the primary responsible party for carrying out the recommendation, including a cost estimate and timeframe for its implementation.

FORMAL SERVICES/WORKFORCE DEVELOPMENT

Recommendation 1.1

Create a state certification in dementia care for facilities, agencies and individuals licensed and monitored by the Colorado Department of Health and the Environment (CDPHE) and the state health professions' licensing boards.

There are few Alzheimer's and dementia care training requirements for health care professionals, paraprofessionals, and facilities and agencies serving consumers with Alzheimer's disease in Colorado. This lack of educational preparation can lead to compromised quality of care, job dissatisfaction and high rates of staff turnover. Although SB 08-153, which authorized licensure of home care agencies in Colorado, requires personal care workers to receive training in dementia care, the requirements do not prescribe curriculum or a required number of hours of training. More educational content and clinical training opportunities have the potential to produce positive outcomes such as fewer incidents, less staff turnover, higher quality of care and higher levels of consumer/resident satisfaction. To ensure that health care providers are trained in dementia care, CDPHE should create and implement evidence-based guidelines for both care providers and facilities. Health and long-term care providers and facilities would have the quality and monetary incentives that come from ensuring staff are well-trained, which translates into satisfied and appropriately cared for consumers with fewer reportable incidents.

The CACC recommends that CDPHE develop a voluntary Certification for Dementia Care Organizations (CDCO) and Certification of Dementia Care Specialists (CDCS). A CDCO will receive special recognition on CDPHE's health facilities licensure website and may advertise as such. CDCSs, upon completion of training by an approved dementia care trainer, will hold a state-granted certificate that can be used in job searches throughout the state.

To become a CDCO, a facility or agency may submit a dementia care training program to the state for certification approval or adopt the curriculum that has been pre-approved by CDPHE. Once approved, the facility would be authorized to conduct Alzheimer's training in house for its staff. In the alternative, a facility or agency can contract with an approved CDCO or certified trainer to provide training onsite. Upon completion of the approved training, employees or job applicants will become CDCSs.

To earn the seal of approval by CDPHE, a facility or agency must ensure that a minimum number of staff have completed the training. To maintain CDCO status, organizations must also have a timetable for training staff and health workers within 90 days of hire.

As an approved CDCO, a facility or agency can train its own employees and offer the training to outside agencies. A direct care worker not employed by an agency or facility can choose to become a CDCS by receiving training from a CDCO. While the CDCS certification is voluntary, it will act like any other certification and is transportable from organization to organization. To maintain a high level of dementia care and CDCO status, an organization must have ongoing training requirements for all staff.

The CACC recommends that 10 hours of pre-employment training be required for all direct care staff and four hours for all other staff. An additional eight hours of annual continuing education dementia training for direct care staff and two hours for all other staff are also recommended.

Responsible entities: Colorado Department of Public Health and Environment Facility Licensing Division.

Costs to the state: Moderate (~\$100,000) to add a section to the facilities licensing statute, to develop and approve curriculum and to add Alzheimer's training requirement to the surveyors' list of requirements to inspect on annual or biennial facility reviews.

Timeline: [SHORT TERM] Because of the high importance of this recommendation, the CACC recommends that the training curriculum be established and approved by December 31, 2011. Once established, CDPHE should monitor its implementation for a period of no more than three years for home care agencies and two years for skilled nursing, assisted-living facilities and adult day care. If an insufficient number of facilities and agencies receive CDCO certification (less than one-third of all licensed facilities/agencies in each licensure category), the General Assembly should consider legislation in 2014 to require certification of all facilities and agencies that care for people with Alzheimer's disease and related dementia.

Recommendation 1.2

Provide targeted opportunities through scholarships and loan repayment programs for geriatric training through the National Health Service Corps (NHSC) and the Colorado Health Service Corps (CHSC).

The CACC recommends that existing and new monies made available through the NHSC and CHSC for scholarships and loan repayment for medical, nursing, social work and other qualifying health professions provide a targeted amount for clinicians who agree to practice in a geriatric setting for their scholarship or loan repayment.

Responsible entities: Colorado Department of Public Health and the Environment Primary Care Office.

Costs to state: Minimal (~\$50,000 to amend marketing materials).

Timeline: [SHORT TERM] Implement by the end of 2011.

Recommendation I.3

Apply for a federal grant to create at least one new Geriatric Education Center in Colorado.

The federal health reform law, the *Patient Protection and Affordable Care Act*, contains a provision to fund additional Geriatric Education Centers under the authority granted to the Bureau of Health Professions in the Health Resources and Services Administration. In addition to providing geriatric curriculum development and clinical training for faculty in medical and other health professions schools, the Geriatric Education Center also must provide family caregiver training by incorporating best practices in training modules. The CACC recommends that the University of Colorado School of Medicine be strongly encouraged to apply for a Geriatric Education Center grant, including assurances that family caregiver training be fully incorporated into the curriculum.

Responsible entity: University of Colorado School of Medicine or the new Interprofessional Training Program in the UC Denver School of Medicine.

Cost to state: Minimal (~\$50,000) for faculty and staff time to develop a grant proposal.

Timeline: [SHORT to MID TERM] Depending on when the federal money is appropriated and whether the School of Medicine determines it has the capacity to house a Geriatric Education Center.

Recommendation I.4

Launch an information campaign to encourage individuals and organizations to apply for grants made available through national health reform to increase educational programs and the number of individuals who are competent to work with older adults who need supportive services with a focus on those with Alzheimer's disease and related dementia.

The federal reform bill, the *Patient Protection and Affordable Care Act*, contains a broad range of grant opportunities to increase educational programs and the number of individuals who are competent to work with older adults with supportive service needs, including those with Alzheimer's disease and related dementia. The CACC recommends that the state's educational programs and service agencies be made aware of these opportunities and encouraged to apply for funding through an information campaign. The grants available for schools and other facilities for training direct care workers are found in Sec. 5302 and professional nurse retention grants in Sec. 5309 of HR 3590. Eligible applicants should be made aware of and encouraged to apply for Geriatric Education Center grants (Sec. 5305) to increase the availability of geriatric training in Colorado.

Responsible entities: Responsibility for the public information campaign should be jointly shared by the state's Aging Services program in the Department of Human Services and the Colorado Chapter of the Alzheimer's Association. Individuals, eligible entities for nurse retention grants (includes an accredited school of nursing, a health care facility or a partnership of such a school and facility) and training opportunities for direct care workers (includes institutions of higher education) should be the target of this information campaign.

Cost to state: Minimal

Timeline: [SHORT to MID TERM] Provisions of the *Patient Protection and Affordable Care Act* are scheduled to be implemented over a period of six years beginning in 2010; the grant programs have been authorized but not all have received an appropriation. The responsible entities should track the implementation schedule of these grant opportunities and make eligible institutions aware of funds as they become available.

Recommendation 1.5

Test new models and expand evidence-based best practices in alternative care facilities (ACFs) caring for individuals with Alzheimer’s disease.

The CACC recommends that if cost savings are realized from the tiered rate study mandated in the Colorado Medicaid Community Long-term Care Savings legislation (HB 10-1053), some of these savings should be earmarked for testing new models of care and expanding best practices in the care of individuals with Alzheimer’s disease and related dementia residing in ACFs.

Responsible entities: Colorado General Assembly, Colorado Department of Health Care Policy and Financing (HCPF), the Colorado Association of Homes and Services for Aging and the Colorado Assisted Living Association.

Cost to state: Minimal state general fund dollars as program enhancements will occur as a result of savings in the nursing home budget line due to implementing the new ACF rate structure.

Timeline: [MID TERM] Once the study has been completed and savings over time estimated, HCPF will monitor anticipated savings and make some proportion of the funds available for implementing best practice programs in Colorado ACFs.

INFORMAL SERVICES/CAREGIVER SUPPORT

Recommendation 2.1

Create a statewide list of licensed attorneys who agree to provide pro bono or reduced-fee elder law services to individuals with Alzheimer’s disease and their families.

When individuals are diagnosed with Alzheimer’s disease, it is recommended that they have a comprehensive legal assessment and secure appropriate legal documents to ensure that their preferences for care and treatment are honored and that their estate, spouse and family members are adequately protected. Such legal documents include medical directives, updated wills and powers of attorney. Securing this legal advice can often present logistic and financial challenges.

Few low-cost legal resources exist to help individuals obtain legal advice when needed. Local Area Agencies on Aging (AAAs) provide free or reduced-cost legal services, but frequently these resources are quite limited and vary by geographic area. Additionally, the Colorado Chapter of the Alzheimer’s Association has contact information for qualified attorneys in Colorado who provide elder law services, but those who provide pro bono or reduced-cost services are not identified. Further exacerbating the

legal access issue is that there are many fewer elder care attorneys listed in many rural areas of the state. The CACC recommends that a statewide list of qualified attorneys who provide pro bono or reduced-cost elder law services to individuals with Alzheimer's disease be created.

Responsible entities: The list would be created through a collaborative effort of the Colorado Bar Association (CBA) and the Colorado Chapter of the Alzheimer's Association. The CBA would be responsible for sending out a letter every other year to all Colorado attorneys in good standing with CBA to identify those willing to provide pro bono or reduced-cost services to individuals diagnosed with Alzheimer's disease. After compiling the list, the CBA would forward the list to the Alzheimer's Association for dissemination.

The list would include a disclaimer that neither the CBA nor the Alzheimer's Association endorses the attorneys on the list and as such cannot be held responsible for the outcomes associated with the attorney consulted. This list would be maintained at the Colorado Chapter of the Alzheimer's Association. Every two years, the CBA would be responsible for forwarding changes to the list to the Alzheimer's Association.

The list would be organized by the 16 AAA regions and distributed to the local AAAs and any other local community aging resource centers. When an individual requests help identifying legal services, the list in its entirety (full list or proper regional section) would be provided to avoid endorsement of a particular attorney.

Cost to state: None.

Timeline: [SHORT to MID TERM] Within three years of adoption of the Alzheimer's State Plan.

Recommendation 2.2

Develop and implement strategies such as increasing the number of dedicated staff to probate courts or creating a volunteer legal services program to monitor and support court-appointed guardianship and conservatorship concerns. Apply for federal grants available through the *Patient Protection and Affordable Care Act* to enhance these adult protective services in Colorado (HR 3590, Sec. 2042).

In February 2010, the *Denver Post* reported on the inconsistencies in the quality and timeliness of addressing guardianship and conservator oversight. Court-appointed guardians and conservators are responsible for managing the finances and other legal affairs of incapacitated adults. These appointees are required to submit yearly reports to the courts about the status of the person they were appointed to protect.

During a 2006 audit of probate courts in Colorado, it was discovered that in 57 percent of the cases reviewed, guardians and conservators had failed to file at least one required report and 17 percent had never filed a required report. Though the system has been revised since the audit, the state still cannot say how many guardians and conservators are filing required reports on time. The required report is the only way the court can monitor the activities of the appointee. Without the report, or some other

method for ensuring that protocols are followed, the court cannot identify and address issues of abuse and neglect.

The CACC recommends that additional staff and/or resources be dedicated to reviewing required reports on a timely basis, that appointees not filing a required report be issued a corrective action plan and that appointees accused of abusive or neglectful actions be immediately relieved of their duties and prosecuted to the fullest extent of the law if found guilty.

Responsible entities: Colorado General Assembly, Colorado Department of Human Services, Colorado probate courts.

Costs to the state: Minimal. Funding for additional staff can be secured by increasing the filing fee for conservators and guardians. National health reform also contains provisions to enhance states' adult protective services programs to prevent elder abuse and financial exploitation of elders.

Timeline: [SHORT TERM] 2011 legislative session.

Recommendation 2.3

Educate employers about the issues facing family caregivers and encourage them to establish workplace policies such as flextime, telecommuting, referral services and on-site support programs.

It is most often a family member who provides the bulk of personal care to an individual diagnosed with Alzheimer's disease. Unpaid caregiving can have a significant impact on the health and well-being of caregivers, as they often must quit their jobs or reduce paid employment to take on unfamiliar and challenging caregiving responsibilities. AARP estimated that in 2008, 34 million informal and unpaid caregivers provided care valued at \$375 billion.

The CACC recommends that employers be educated about the issues facing family caregivers and provided options for establishing workplace policies such as flextime, telecommuting, referral services and on-site support programs. The Family Medical Leave Act (FMLA) should also be highlighted for those employers subject to its provisions.

Responsible entities: The Colorado Department of Labor and Employment (CDLE), the Area Health Education Centers and the Colorado Chapter of the Alzheimer's Association could collaborate to provide educational materials and encouragement to employers to establish workplace policies and/or offer programs to support their employees.

CDLE could develop worksite posters and related materials with information about family caregiving as it relates to the FMLA to be distributed to Colorado employers. Materials should include a website for more information and resources. The materials should be available through a number of venues, including the CDLE, Department of Human Services, State Unit on Aging and the websites of local Area Agencies on Aging.

The Colorado Chapter of the Alzheimer’s Association could include information about family caregiving coverage under the FMLA in its presentations and trainings for caregivers, as well as conducting employer trainings about flexible and supportive workplaces, as requested.

Costs to state: Minimal, to prepare and disseminate materials through CDLE.

Timeline: [SHORT TERM]. Within two years of the adoption of the Alzheimer’s State Plan.

Recommendation 2.4

Ensure that local Area Agencies on Aging (AAAs) are aware of and promote existing training materials available to family caregivers, especially those located in rural areas.

Responsible entities: The Colorado Chapter of the Alzheimer’s Association has a curriculum developed for employers and family caregivers that can be offered through the local AAAs. The State Unit on Aging should encourage AAAs to promote this programming.

Costs to state: Minimal.

Timeline: Ongoing.

Recommendation 2.5

Increase funding for and expand the reach of the Savvy Caregiver program and equivalent training programs for all stages of dementia.⁶

If savings are identified from the ACF tier-rate study required by HB 10-1053 and ultimately accrue due to changes in rate setting, the CACC recommends using a portion of the savings to increase funding for the *Savvy Caregiver* and other training programs currently offered by the Colorado Chapter of the Alzheimer’s Association. These training programs equip family caregivers with the tools they need to care for the family member with Alzheimer’s as well as themselves. Although *Savvy Caregiver* and similar training programs do not get people out of nursing homes, they may delay placement because family members are better able to provide appropriate and quality care at home. Currently, the *Savvy Caregiver* program is offered a minimum of 16 times per year in the Denver area and another 14 times throughout the state. More funding would help the program meet the increased demand for training around the state.

Responsible entities: Colorado State Unit on Aging and Colorado Chapter of the Alzheimer’s Association.

Cost to state: Moderate.

Timeline: [MID TERM]

⁶ A CACC member expressed concerns that if savings from HB10 1053 are realized, they should not be used toward other programs, but rather that the money should follow the person out of the nursing home into a lesser level of care. In most cases, savings will be realized from individuals moving out of nursing homes into ACFs; therefore the money should be invested in the alternative care facility in which the person resides and not used for other programs.

QUALITY AND RESEARCH

Recommendation 3.1

Add an Alzheimer's module to the Colorado Behavior Risk Factor Surveillance Survey (BRFSS) to collect state-level data on the prevalence of Alzheimer's disease and associated characteristics such as living arrangements, family and caregiver needs and responsibilities.

Population surveillance is a public health tool used to collect and analyze data that identifies risk factors for disease and, when identified, support strategies to reduce risks. The BRFSS is conducted annually by the Colorado Department of Public Health and Environment (CDPHE) and consists of a core set of questions asked in every state and optional modules states can add at the cost of the module. Colorado's BRFSS survey currently does not include any questions related to Alzheimer's disease.

The CACC recommends that an Alzheimer's module be developed and added to the Colorado BRFSS to collect state-level data about the prevalence of Alzheimer's disease including family characteristics and living arrangements of Alzheimer's patients. Using the BRFSS would be a relatively low-cost method for obtaining population prevalence that could inform policymakers and increase public awareness of the societal impact of Alzheimer's disease.

Responsible entities: CDPHE and the Colorado Chapter of the Alzheimer's Association.

Cost to the state: Minimal (~\$50,000 annually).

Timeline: [SHORT to MID TERM] A CDPHE-appointed committee reviews and approves additional modules each year to the BRFSS. The timeframe would be dependent on the committee's approval of an Alzheimer's module.

Recommendation 3.2

Establish a Colorado Alzheimer's Disease Research Center at the University of Colorado School of Medicine.

Although the University of Colorado School of Medicine ranked 27th in the *U.S. News and World Report* Best Medical Schools Research Rankings, the school currently conducts very little Alzheimer's-related research. Alzheimer's Disease Research Centers (ADRC) are funded by the National Institutes of Health and work to advance better care and diagnosis for Alzheimer's disease, while striving to reach the ultimate goal of finding a cure. The Rocky Mountain West region currently does not have an ADRC.⁷ The CACC recommends that the University of Colorado School of Medicine apply to become an ADRC to increase the level of Alzheimer's disease research occurring in Colorado and the Rocky Mountain West region.

⁷ The Neurology Department at the University of Colorado School of Medicine recently received private grants that will enable it to recruit new faculty to expand the department's clinical and research presence in the area of Alzheimer's disease. There do not appear to be additional resources outside of the Neurology Department to make an Alzheimer's Center a likely reality at the present time. [Communication from Kenneth L Tyler, MD, Reuler-Lewin family professor and chair, Neurology Department, University of Colorado School of Medicine.]

Responsible entity: University of Colorado School of Medicine, Department of Neurology.

Costs to the state: Minimal-to-moderate depending on the level of state funds needed to match or make such a research center a viable enterprise.

Timeline: [MID TERM]. The University should apply within the next five years.

Recommendation 3.3

Conduct an evidence-based review of transitions of care models with a focus on patients with Alzheimer’s disease and related dementia, with the intent of authorizing two to three pilot programs in Colorado to test best-practice approaches.

Because of inconsistent standards and protocols for the efficient transitioning of Alzheimer’s patients between institutional care and community-based settings, unnecessarily long and inappropriate hospital or nursing home stays occur when community care is the setting of choice for patients and their informal caregivers.

Promising initiatives are underway in Colorado, for example, Dr. Eric Coleman’s transitions-of-care model that has been implemented in a number of Colorado settings. The CACC recommends that an evidence-based review be conducted of best practices in this area with a focus on patients with Alzheimer’s disease and related dementia.

Once the review has been completed, the CACC recommends the Colorado Department of Health Care Policy and Financing (HCPF) be empowered to authorize two to three pilot programs in the state that are specific to hospitalized patients with Alzheimer’s disease to test the appropriateness and cost-effectiveness of these approaches.

Responsible entities: Colorado General Assembly and HCPF.

Costs to the state: Minimal-to-moderate. Up to \$50,000 to complete the evidence-based review, HCPF staff time to develop the RFP and *Patient Protection and Affordable Care Act* grants to conduct the pilot studies and their evaluation.

Timeline: [SHORT to MID TERM]. 2011 legislative session for authorizing legislation to conduct study and three to five years to conduct and evaluate pilots.

Recommendation 3.4

Establish a senior policy advisor on aging and long-term care in the Governor’s Office of Policy and Initiatives.

A number of states have cabinet-level positions that advise the governor on aging and long-term care policy issues. In Colorado, responsibility for aging and LTC policy formulation and administration is scattered among several state departments. Re-organization of state governmental agencies is less imperative than having an expert adviser with the authority to direct state agencies to work together and to be responsive to the overall policy direction emanating from the Governor’s Office.

The CACC recommends that the Governor's Office of Policy and Initiatives include a senior adviser on aging and long-term care issues to advise the governor and provide overall direction for the administration in this critical policy area. This senior policy adviser would be responsible for coordinating efforts across state departments and promoting evidence-based, best-practice policies into the administration's policy agenda.

Responsible entity: Governor's Office.

Costs to state: Minimal (~\$100,000 per year).

Timeline: [SHORT to MID TERM]. With the election of a new governor in 2010 who will assume office in January 2011, this position could be appointed as soon as 2011.

Recommendation 3.5

Support the Seniors Mental Health Access Improvement Act of 2009, federal legislation to provide reimbursement to marriage and family therapists and mental health counselors under Part B of Medicare.

Many people with Alzheimer's disease and other dementias experience high levels of stress while receiving care. Higher stress often leads to behavioral problems that are difficult for caregivers to address. In the institutional setting, behavioral problems sometimes arise, creating safety issues for staff and other individuals. However, having a properly trained staff to help alleviate stress and provide counseling for individuals can greatly reduce the risk of serious behavioral problems. Further, growing evidence suggests that counseling and socio-behavioral interventions can be beneficial not only for behavior management but also in enhancing the functioning of individuals with Alzheimer's disease, increasing their quality of life and reducing caregiver stress. In some cases, it might also be cost effective to use counseling and socio-behavioral techniques as opposed to medication management.

Responsible entity: The CACC will bring this recommendation forward to the joint Health and Human Services committee of the General Assembly in January 2011.

Cost to the state: None.

Timeline: [SHORT TERM]. January 2011.

PUBLIC SAFETY AND PUBLIC AWARENESS

Recommendation 4.1

Create and circulate a form that physicians and optometrists can fill out and send to the Driver Control/Traffic Records Section of the Colorado Department of Motor Vehicles (DMV).

As Alzheimer's disease progresses, an individual's ability to drive safely is diminished. Considerable anxiety exists around telling individuals that they should no longer be driving. Currently, the Colorado DMV has the authority to cancel, deny or deny reissuance of a driver's license for several reasons,

including the inability to operate a motor vehicle because of physical or mental incompetence. Though the department may use the written medical opinion of a physician, physician's assistant or optometrist licensed in Colorado in deciding to renew, suspend, revoke or cancel a drivers' license, there is not a uniform or user-friendly process for doctors to report a medical opinion to the DMV.

The CACC recommends that a single form be developed to be distributed to offices where physicians, physician assistants, nurse practitioners and optometrists work that can inform a local DMV office of an individual's inability to continue operating a motor vehicle. Further, the CACC recommends an education and outreach campaign be launched to inform health care providers about ways to address driving issues with patients and their families and then make appropriate contact with the DMV. The outreach campaign should include physician residency programs in Colorado, medical societies, nurse associations, other medical professional societies, hospitals and assisted-living facilities.

The CACC recommends that the Colorado Chapter of the Alzheimer's Association work with the Postgraduate Institute for Medicine, a continuing medical education provider, to develop a curriculum module about safety issues associated with patients with Alzheimer's disease and other dementias. The module should include the newly created form.

Responsible entities: The DMV, University of Colorado School of Medicine and Colorado Chapter of the Alzheimer's Association.

Costs to state: Minimal to develop uniform form for health care providers.

Timeline: [SHORT TERM]. Within three years of adopting Alzheimer's State Plan.

Recommendation 4.2

Collaborate with and leverage the national Alzheimer's Association's public awareness campaign and related efforts to encourage the utilization of public service announcements through local radio and television stations, as well as other public awareness venues.

The Colorado public, as elsewhere, has a limited understanding of the signs and symptoms associated with the diagnosis and treatment of Alzheimer's disease. Issues range from a basic knowledge of early warning signs of the disease to recognizing a lost or endangered person.

The national Alzheimer's Association has launched a new public awareness campaign to educate the public about the 10 warning signs of Alzheimer's disease and the benefits that accrue to individuals and families from a better awareness of early detection. The campaign has developed several print ads and a television commercial.

The CACC recommends that older adult service organizations including the State unit on Aging (SUA) and AAAs collaborate with the Colorado Chapter of the Alzheimer's Association to ensure that the national awareness campaign is widely disseminated in Colorado. Along with the national campaign, local public awareness campaigns should be enhanced and further developed, through public service announcements and other information dissemination outlets. Further, the CACC recommends that

materials developed by the Alzheimer’s Association be distributed to insurance companies and health plans in Colorado to disseminate to their enrollees.

Responsible entities: Colorado Chapter and national Alzheimer’s Association and related organizations.

Costs to state: None.

Timeline: [SHORT TERM]. 2011 and beyond.

Recommendation 4.3

Increase the visibility and utilization of locator devices and programs.

Wandering is one of the most significant personal safety risks faced by individuals with Alzheimer’s disease—nearly 60 percent of people with Alzheimer’s wander at some point during the course of their disease. Approximately half of all wanderings result in personal injury if the individual is not found within 24 hours. Although several programs and devices have been developed to reduce the risk of wandering, these methods are underutilized in Colorado.

The CACC recommends that a public awareness campaign be launched to educate the public about the relative effectiveness of locator devices with the goal of increasing their utilization. The Alzheimer’s Association has developed *Comfort Zone*, which is a GPS tracking locator device (a pager or watch connected to satellite signals). Other devices and programs that have an evidence-basis for their effectiveness include *Project Lifesaver*.

Responsible entities: Colorado Department of Public Safety and the Police Officers Standards and Training Board (POST).

Costs to state: Minimal for public information campaign (up to \$100,000).

Timeline: [SHORT TERM]. Within two years of the approval of the Alzheimer’s State Plan.

Recommendation 4.4

Implement a gatekeeper model of case finding throughout the state to identify individuals with Alzheimer’s disease who are at risk in the community.

Often individuals with Alzheimer’s disease who are wandering, lost or otherwise in a dangerous situation are not immediately recognizable as at risk; that is, the warning signs are not readily apparent. Because the general public is unaware of the situations and signs that put an individual at risk, appropriate community responses cannot be expected.

The “gatekeeper model of case finding” trains community gatekeepers such as bank tellers, mail carriers, housing managers and other employees of businesses and organizations that are likely to come into contact with older adults to identify those in need of assistance. Trained gatekeepers make referrals to a

centralized point of contact where the individual is triaged to an appropriate agency for assessment and referral.

The CACC recommends that the Colorado SUA work with the local AAAs to implement this program throughout the state. The CACC also recommends that the SUA, in collaboration with the Colorado Chapter of the Alzheimer's Association, work with large employers in Colorado to offer a short training module for their employees about recognizing the signs of wandering and/or lost individuals.

Responsible entities: State Unit on Aging, Area Agencies on Aging and employers.

Costs to state: Minimal. The costs associated with developing curriculum content and disseminating the module to AAAs and their staffs can likely be covered by Older American Act funds.

Timeline: [SHORT TERM]. Within three years of the approval of the Alzheimer's State Plan.

Recommendation 4.5

Encourage and enhance adequate training for first responders about medical and behavioral issues related to Alzheimer's disease and related dementias when responding to an emergency involving these individuals.

First responders play an important role in keeping individuals with Alzheimer's disease safe. When an individual with Alzheimer's disease has gone missing or finds himself/herself in a difficult situation, it is often a first responder's job to diffuse the situation and/or provide required supervision and protective services. It is important for first responders to have the knowledge and tools at their fingertips to respond appropriately when needed. The Alzheimer's Association has developed a short curriculum to train first responders in four content areas: 1) wandering; 2) driving, firearms and shoplifting; 3) abuse and neglect; and, 4) disaster response.

The CACC recommends that police departments, fire departments and hospital emergency departments are providing dementia training to all first responders. Materials for the training are available through the Colorado Chapter of the Alzheimer's Association and can be provided in-person or with a one-hour DVD. Further, it is recommended that the POST board adopt specific a dementia training module.

Responsible entities: Local police and fire departments, hospitals, the POST board and the Colorado Chapter of the Alzheimer's Association.

Costs to state: Minimal, the costs associated with disseminating information and adopting the training module.

Timeline: [SHORT TERM]. Within three years of the approval of the Alzheimer's State Plan.

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NOTE: This bill has been prepared for the signature of the appropriate legislative officers and the Governor. To determine whether the Governor has signed the bill or taken other action on it, please consult the legislative status sheet, the legislative history, or the Session Laws.



SENATE BILL 08-058

BY SENATOR(S) Boyd, Bacon, Gordon, Isgar, Penry, Spence, Tochtrop, Gibbs, Groff, Morse, Shaffer, Veiga, Ward, Williams, and Windels; also REPRESENTATIVE(S) Riesberg, Gagliardi, Green, Kerr J., Mitchell V., Todd, Buescher, Butcher, Carroll M., Carroll T., Gallegos, Garza-Hicks, Hodge, Kefalas, Kerr A., Levy, Madden, McFadyen, McGihon, Merrifield, Middleton, Peniston, Primavera, Roberts, Romanoff, Solano, and Stafford.

CONCERNING THE CREATION OF THE COLORADO ALZHEIMER'S COORDINATING COUNCIL TO DEVELOP A STATE PLAN TO ADDRESS THE INCREASE IN THE INCIDENCE OF ALZHEIMER'S DISEASE IN THE STATE.

Be it enacted by the General Assembly of the State of Colorado:

SECTION 1. Title 25, Colorado Revised Statutes, is amended BY THE ADDITION OF A NEW ARTICLE to read:

ARTICLE 38
Colorado Alzheimer's Coordinating Council

25-38-101. Short title. THIS ARTICLE SHALL BE KNOWN AND MAY BE CITED AS THE "COLORADO ALZHEIMER'S COORDINATING COUNCIL ACT".

Capital letters indicate new material added to existing statutes; dashes through words indicate deletions from existing statutes and such material not part of act.

25-38-102. Legislative declaration. (1) THE GENERAL ASSEMBLY HEREBY FINDS AND DECLARES THAT:

(a) CURRENTLY, APPROXIMATELY SIXTY-FIVE THOUSAND COLORADANS ARE LIVING WITH ALZHEIMER'S DISEASE, AND THAT NUMBER IS PROJECTED TO INCREASE ONE HUNDRED TWENTY-FOUR PERCENT BY THE YEAR 2025, AFFECTING AN ESTIMATED ONE HUNDRED FORTY THOUSAND PEOPLE IN THE STATE;

(b) NEARLY SIXTY PERCENT OF ALL NURSING HOME RESIDENTS IN COLORADO HAVE ALZHEIMER'S DISEASE OR ANOTHER FORM OF DEMENTIA, WITH NEARLY FIFTY PERCENT OF THE COSTS OF THOSE RESIDENTS PAID FOR THROUGH THE STATE MEDICAID PROGRAM;

(c) ADDITIONALLY, THE DISEASE HAS A DEVASTATING EFFECT ON FAMILIES, WITH NEARLY SEVENTY PERCENT OF INDIVIDUALS WITH THE DISEASE LIVING AT HOME AND NEARLY FORTY PERCENT OF FAMILY CAREGIVERS REPORTING HIGH LEVELS OF EMOTIONAL AND FINANCIAL STRESS THAT IMPACTS THEIR JOB PERFORMANCE;

(d) THE LOST PRODUCTIVITY OF EMPLOYEES WHO ARE CAREGIVERS OF ALZHEIMER'S DISEASE PATIENTS AND THE COSTS OF THE RESULTANT HEALTH CARE AND LONG-TERM CARE ADD SUBSTANTIALLY TO THE COST OF DOING BUSINESS IN THE STATE;

(e) THE EPIDEMIC GROWTH IN THE NUMBER OF INDIVIDUALS DIAGNOSED WITH ALZHEIMER'S DISEASE AND THE RESULTANT HEALTH CARE COSTS ASSOCIATED WITH THE TREATMENT AND CARE OF DIAGNOSED INDIVIDUALS THREATENS THE PUBLIC AND PRIVATE HEALTH CARE SYSTEMS IN THE STATE; AND

(f) ALZHEIMER'S DISEASE COSTS THE STATE AND PRIVATE BUSINESSES BILLIONS OF DOLLARS EACH YEAR.

(2) THE GENERAL ASSEMBLY FURTHER FINDS AND DECLARES THAT IT IS IMPORTANT:

(a) FOR THE PUBLIC AND PRIVATE SECTORS TO COORDINATE EXPERTISE OVER A BROAD SPECTRUM AND PROVIDE COLORADO WITH SHORT- AND LONG-TERM PLANNING TO RESPOND TO THE ALZHEIMER'S DISEASE

EPIDEMIC; AND

(b) TO DEVELOP A COLORADO-SPECIFIC ALZHEIMER'S DISEASE PLAN TO IDENTIFY THE INFRASTRUCTURE AND ACCOUNTABILITY NECESSARY TO BUILD DEMENTIA-CAPABLE PROGRAMS TO HELP COLORADO DEAL WITH THE GROWING NUMBER OF ALZHEIMER'S DISEASE PATIENTS AND TO MANAGE THE IMPACT ON FAMILY CAREGIVERS, PATIENTS, AND PUBLIC AND PRIVATE EMPLOYERS IN THE STATE.

(3) THE GENERAL ASSEMBLY FURTHER DETERMINES THAT IT IS NECESSARY TO CREATE A COUNCIL OF STAKEHOLDERS AND POLICYMAKERS TO DEVELOP A COMPREHENSIVE STATE PLAN ON A RANGE OF ISSUES THAT IMPACT PUBLIC POLICY DECISIONS, INCLUDING, WITHOUT LIMITATION:

(a) THE AVAILABILITY OF DIAGNOSTIC SERVICES;

(b) THE SAFETY OF PERSONS WITH ALZHEIMER'S DISEASE WHO WANDER AWAY FROM THEIR HOME OR OTHER LOCATION;

(c) STATE INSTITUTION-BASED RESEARCH;

(d) MEDICAID COVERAGE FOR LONG-TERM CARE FOR THOSE ALZHEIMER'S DISEASE PATIENTS AND FAMILIES THAT CANNOT AFFORD THE COSTS OF LONG-TERM CARE; AND

(e) THE QUALITY AND AVAILABILITY OF HEALTH CARE SERVICES FOR ALZHEIMER'S DISEASE PATIENTS AND THEIR CAREGIVERS.

25-38-103. Definitions. AS USED IN THIS ARTICLE, UNLESS THE CONTEXT OTHERWISE REQUIRES:

(1) "COUNCIL" MEANS THE COLORADO ALZHEIMER'S COORDINATING COUNCIL CREATED IN SECTION 25-38-104.

(2) "DESIGNATED ORGANIZATION" MEANS THE NONPROFIT OR PRIVATE ORGANIZATION DESIGNATED BY THE PRESIDENT OF THE SENATE AND THE SPEAKER OF THE HOUSE OF REPRESENTATIVES PURSUANT TO SECTION 25-38-107 (1) AS THE CUSTODIAN OF FUNDS FOR THE COUNCIL.

(3) "PARTICIPATING STATE DEPARTMENTS" MEANS THE

DEPARTMENTS OF HUMAN SERVICES, HEALTH CARE POLICY AND FINANCING, PUBLIC HEALTH AND ENVIRONMENT, PUBLIC SAFETY, AND LABOR AND EMPLOYMENT, OR THEIR SUCCESSOR DEPARTMENTS.

(4) "STATE PLAN" MEANS THE COLORADO STATE PLAN FOR ALZHEIMER'S DISEASE DEVELOPED BY THE COUNCIL PURSUANT TO THIS ARTICLE.

25-38-104. Colorado Alzheimer's coordinating council - creation - membership - procedures. (1) THERE IS HEREBY CREATED IN THE LEGISLATIVE BRANCH THE COLORADO ALZHEIMER'S COORDINATING COUNCIL, WHICH SHALL BE CHARGED WITH ASSESSING THE CURRENT AND FUTURE IMPACT OF ALZHEIMER'S DISEASE IN COLORADO AND FORMULATING A COLORADO STATE PLAN FOR ALZHEIMER'S DISEASE TO ADDRESS THE IMPACTS OF THE DISEASE IN THE STATE.

(2) THE COUNCIL SHALL BE COMPOSED OF TWENTY-TWO MEMBERS AS FOLLOWS:

(a) THE PRESIDENT OF THE SENATE AND THE SPEAKER OF THE HOUSE OF REPRESENTATIVES SHALL JOINTLY APPOINT ELEVEN MEMBERS AS FOLLOWS:

(I) ONE MEMBER WHO IS DIAGNOSED WITH EARLY-STAGE ALZHEIMER'S DISEASE;

(II) ONE MEMBER WHO IS OR HAS BEEN THE CAREGIVER OF A PERSON WITH ALZHEIMER'S DISEASE;

(III) ONE MEMBER WHO REPRESENTS THE NURSING HOME INDUSTRY;

(IV) ONE MEMBER WHO REPRESENTS THE ASSISTED LIVING INDUSTRY;

(V) ONE MEMBER WHO REPRESENTS THE ADULT DAY SERVICES INDUSTRY;

(VI) ONE MEMBER WHO REPRESENTS THE MEDICAL CARE PROVIDER COMMUNITY;

(VII) ONE MEMBER WHO REPRESENTS A HOSPITAL LICENSED OR CERTIFIED IN THE STATE;

(VIII) ONE MEMBER WHO IS AN ALZHEIMER'S DISEASE RESEARCHER;

(IX) ONE MEMBER WHO REPRESENTS THE ALZHEIMER'S ASSOCIATION COLORADO CHAPTER;

(X) ONE MEMBER REPRESENTING THE BUSINESS COMMUNITY; AND

(XI) THE STATE LONG-TERM CARE OMBUDSMAN, AS DEFINED IN SECTION 26-11.5-103, C.R.S., OR A LOCAL OMBUDSMAN, AS DEFINED IN SECTION 26-11.5-103, C.R.S., THAT IS RECOMMENDED TO THE PRESIDENT AND THE SPEAKER BY THE STATE LONG-TERM CARE OMBUDSMAN;

(b) THE PRESIDENT OF THE SENATE SHALL APPOINT ONE MEMBER WHO SERVES IN THE SENATE;

(c) THE SPEAKER OF THE HOUSE OF REPRESENTATIVES SHALL APPOINT ONE MEMBER WHO SERVES IN THE HOUSE OF REPRESENTATIVES;

(d) THE MINORITY LEADER OF THE SENATE SHALL APPOINT ONE MEMBER WHO SERVES IN THE SENATE;

(e) THE MINORITY LEADER OF THE HOUSE OF REPRESENTATIVES SHALL APPOINT ONE MEMBER WHO SERVES IN THE HOUSE OF REPRESENTATIVES;

(f) THE GOVERNOR SHALL APPOINT TWO MEMBERS, ONE OF WHOM SHALL BE A MENTAL HEALTH PROFESSIONAL AND ONE OF WHOM SHALL REPRESENT HOME CARE AGENCIES; AND

(g) THE EXECUTIVE DIRECTORS OF EACH OF THE FIVE PARTICIPATING STATE DEPARTMENTS OR THEIR DESIGNEES.

(3) THE APPOINTING AUTHORITIES SHALL MAKE APPOINTMENTS TO THE COUNCIL BY DECEMBER 1, 2008, TO ALLOW THE COUNCIL TO BEGIN MEETING NO LATER THAN MARCH 1, 2009.

(4) THE COUNCIL SHALL ELECT A CHAIR AND VICE-CHAIR FROM

AMONG ITS MEMBERS. MEMBERS OF THE COUNCIL SHALL SERVE WITHOUT COMPENSATION BUT MAY BE REIMBURSED FOR ALL ACTUAL AND NECESSARY EXPENSES INCURRED IN THE PERFORMANCE OF THEIR DUTIES.

(5) THE COUNCIL SHALL MEET AT LEAST QUARTERLY OR MORE OFTEN AS DEEMED NECESSARY BY THE COUNCIL. MEETINGS OF THE COUNCIL SHALL BE OPEN TO THE PUBLIC IN ACCORDANCE WITH PART 4 OF ARTICLE 6 OF TITLE 24, C.R.S., AND RECORDS OF THE COUNCIL SHALL BE OPEN FOR PUBLIC INSPECTION IN ACCORDANCE WITH PART 2 OF ARTICLE 72 OF TITLE 24, C.R.S.

(6) THE COUNCIL MAY:

(a) ADOPT RULES OF PROCEDURE IT DEEMS NECESSARY TO FACILITATE THE ORDERLY CONDUCT OF ITS BUSINESS;

(b) ESTABLISH TASK FORCES OR COMMITTEES OF ITS MEMBERS AND OTHERS TO ASSIST IN THE PERFORMANCE OF THE COUNCIL'S DUTIES; AND

(c) ACCEPT WRITTEN OR ORAL INPUT FROM THE PUBLIC AND ANY RELEVANT SOURCE.

25-38-105. Council duties and responsibilities - assessment of Alzheimer's disease - development of plan. (1) THE COUNCIL SHALL:

(a) ASSESS THE CURRENT AND FUTURE IMPACT OF ALZHEIMER'S DISEASE ON THE RESIDENTS OF COLORADO;

(b) SOLICIT AND GATHER INFORMATION NECESSARY FOR REVIEW AND DISCUSSION BY THE COUNCIL;

(c) GATHER FEEDBACK FROM INDIVIDUALS AND FAMILIES AFFECTED BY ALZHEIMER'S DISEASE AS WELL AS FROM THE GENERAL PUBLIC;

(d) REVIEW THE AVAILABILITY OF EXISTING INDUSTRIES, SERVICES, AND RESOURCES ADDRESSING THE NEEDS OF INDIVIDUALS WITH ALZHEIMER'S DISEASE, THEIR FAMILIES, AND THEIR CAREGIVERS;

(e) DEVELOP A STRATEGY TO MOBILIZE A STATE RESPONSE TO THE INCREASING INCIDENCE OF ALZHEIMER'S DISEASE IN COLORADO;

(f) CONSIDER OTHER ISSUES RELATED TO ALZHEIMER'S DISEASE THAT ARE IDENTIFIED BY THE COUNCIL;

(g) FORMULATE A COMPREHENSIVE STATE PLAN FOR ADDRESSING ALZHEIMER'S DISEASE THAT INCLUDES A SHORT- AND LONG-TERM PLAN FOR CONFRONTING THE CHALLENGES PRESENTED BY THE RAPID GROWTH IN THE ALZHEIMER'S DISEASE POPULATION; AND

(h) SUBMIT A REPORT OF ITS FINDINGS AND DATE-SPECIFIC RECOMMENDATIONS FOR STATUTORY, ADMINISTRATIVE RULE, AND PROCEDURE CHANGES TO THE GOVERNOR, GENERAL ASSEMBLY, AND PARTICIPATING STATE DEPARTMENTS, IN THE FORM OF A COLORADO STATE PLAN FOR ALZHEIMER'S DISEASE.

(2) THE COUNCIL'S ASSESSMENT AND RECOMMENDATIONS SHALL INCLUDE AN EXAMINATION OF AT LEAST THE FOLLOWING:

(a) TRENDS IN THE STATE'S ALZHEIMER'S DISEASE POPULATION AND NEEDS, INCLUDING THE CHANGING SIZE AND NATURE OF THE POPULATION WITH DEMENTIA. IN ITS EXAMINATION OF THESE TRENDS, THE COUNCIL SHALL REVIEW:

(I) THE STATE'S ROLE IN LONG-TERM CARE, FAMILY CAREGIVER SUPPORT, AND ASSISTANCE TO PERSONS WITH EARLY-STAGE AND EARLY ONSET OF ALZHEIMER'S DISEASE; AND

(II) THE STATE'S POLICY REGARDING PERSONS WITH ALZHEIMER'S DISEASE AND DEVELOPMENTAL DISABILITIES.

(b) EXISTING SERVICES, RESOURCES, AND CAPACITY, INCLUDING, BUT NOT LIMITED TO, THE FOLLOWING:

(I) THE TYPE, COSTS, AND AVAILABILITY OF DEMENTIA SERVICES;

(II) DEMENTIA-SPECIFIC TRAINING REQUIREMENTS FOR LONG-TERM CARE STAFF;

(III) QUALITY CARE MEASURES FOR RESIDENTIAL CARE FACILITIES;

(IV) THE CAPACITY OF PUBLIC SAFETY AND LAW ENFORCEMENT

AGENCIES TO RESPOND TO INDIVIDUALS WITH ALZHEIMER'S DISEASE;

(V) THE AVAILABILITY OF HOME- AND COMMUNITY-BASED RESOURCES FOR INDIVIDUALS WITH ALZHEIMER'S DISEASE AND THE AVAILABILITY OF RESPITE CARE TO ASSIST FAMILIES;

(VI) AN INVENTORY OF LONG-TERM CARE FACILITIES OR DEMENTIA CARE UNITS IN THE STATE;

(VII) THE ADEQUACY AND APPROPRIATENESS OF GERIATRIC-PSYCHIATRIC SERVICES FOR INDIVIDUALS WITH BEHAVIOR DISORDERS ASSOCIATED WITH ALZHEIMER'S DISEASE AND RELATED DEMENTIA;

(VIII) ASSISTED-LIVING RESIDENTIAL OPTIONS FOR INDIVIDUALS WITH DEMENTIA; AND

(IX) STATE SUPPORT OF ALZHEIMER'S DISEASE RESEARCH THROUGH THE STATE INSTITUTIONS OF HIGHER EDUCATION AND THROUGH OTHER RESOURCES;

(c) EVIDENCE-BASED, BEST PRACTICE STRATEGIES DEVELOPED BY PROFESSIONAL ORGANIZATIONS OR IDENTIFIED BY ALZHEIMER'S DISEASE OR DEMENTIA PLANS IN OTHER STATES TO HELP REDUCE THE OVERWHELMING COSTS OF DEMENTIA; AND

(d) NECESSARY STATE POLICIES OR RESPONSES, INCLUDING, BUT NOT LIMITED TO, THE FOLLOWING:

(I) DIRECTIONS FOR THE PROVISION OF CLEAR AND COORDINATED SERVICES AND SUPPORT TO INDIVIDUALS AND FAMILIES LIVING WITH ALZHEIMER'S DISEASE AND RELATED DISORDERS; AND

(II) STRATEGIES TO ADDRESS ANY IDENTIFIED GAPS IN SERVICES FOR ALZHEIMER'S DISEASE PATIENTS AND THEIR FAMILIES AND CAREGIVERS.

(3) THE COUNCIL SHALL NOT PARTICIPATE IN INFORMATION GATHERING, DISCUSSIONS, OR DECISIONS RELATING TO THE CARE OF INDIVIDUAL ALZHEIMER'S DISEASE PATIENTS.

25-38-106. Council report - joint legislative meeting. (1) NO LATER THAN EIGHTEEN MONTHS AFTER THE COUNCIL'S FIRST MEETING, THE COUNCIL SHALL SUBMIT AN INITIAL REPORT OF ITS FINDINGS AND DATE-SPECIFIC RECOMMENDATIONS FOR STATUTORY, ADMINISTRATIVE RULE, AND PROCEDURE CHANGES TO THE GOVERNOR, THE GENERAL ASSEMBLY, AND THE PARTICIPATING STATE DEPARTMENTS, IN THE FORM OF A STATE PLAN FOR ALZHEIMER'S DISEASE. THE INITIAL REPORT SHALL INCLUDE THE EXAMINATION OF THE ISSUES DESCRIBED IN SECTION 25-38-105 (2) AND THE COUNCIL'S RECOMMENDATIONS BASED ON SUCH EXAMINATIONS. THE COUNCIL MAY SUBMIT SUPPLEMENTAL REPORTS OR DATA AS NECESSARY TO CLARIFY OR EXPAND UPON ISSUES IN THE INITIAL REPORT OR UPON REQUEST OF THE PERSONS OR ENTITIES REVIEWING THE INITIAL REPORT.

(2) WITHIN SIX MONTHS AFTER SUBMISSION OF THE COUNCIL'S INITIAL REPORT, THE CHAIRS OF THE HEALTH AND HUMAN SERVICES COMMITTEES OF THE SENATE AND HOUSE OF REPRESENTATIVES OR THEIR SUCCESSOR COMMITTEES SHALL CONVENE AT LEAST ONE JOINT MEETING OF THEIR RESPECTIVE COMMITTEES, THE GOVERNOR OR THE GOVERNOR'S DESIGNEE, AND THE PARTICIPATING STATE DEPARTMENTS TO REVIEW THE COUNCIL'S INITIAL REPORT AND ANY SUPPLEMENTAL REPORTS OR DATA SUBMITTED BY THE COUNCIL AND CONSIDER THE COUNCIL'S RECOMMENDATIONS THAT MAY IMPACT THE STATE'S HEALTH CARE SYSTEM AND THE STATE BUDGET. BASED ON THEIR REVIEW OF THE COUNCIL'S REPORT, MEMBERS OF THE GENERAL ASSEMBLY, THE GOVERNOR, OR THE PARTICIPATING STATE DEPARTMENTS MAY RECOMMEND STRATEGIES TO IMPROVE SERVICES AND SUPPORT TO INDIVIDUALS AND FAMILIES LIVING WITH ALZHEIMER'S DISEASE.

25-38-107. Alzheimer's coordinating council - designation of organization to accept donations - authority to engage staff support - creation of cash fund. (1) (a) THE SPEAKER OF THE HOUSE OF REPRESENTATIVES AND THE PRESIDENT OF THE SENATE SHALL DESIGNATE A NONPROFIT OR PRIVATE ORGANIZATION AS THE CUSTODIAN OF FUNDS FOR THE COUNCIL. THE DESIGNATED ORGANIZATION IS AUTHORIZED TO RECEIVE AND EXPEND ANY FUNDS NECESSARY FOR THE OPERATION OF THE COUNCIL AND MAY SOLICIT AND ACCEPT MONETARY AND IN-KIND GIFTS, GRANTS, AND DONATIONS FOR USE IN FURTHERANCE OF THE COUNCIL'S DUTIES AND RESPONSIBILITIES. ANY MONEYS DONATED OR AWARDED TO THE DESIGNATED ORGANIZATION FOR THE BENEFIT OF THE COUNCIL ARE NOT SUBJECT TO APPROPRIATION BY THE GENERAL ASSEMBLY, AND ANY SUCH

MONEYS THAT ARE UNEXPENDED AND UNENCUMBERED AT THE TIME THE COUNCIL IS DISSOLVED OR THIS ARTICLE REPEALS PURSUANT TO SECTION 25-38-108 SHALL BE RETURNED TO THE DONORS OR GRANTORS ON A PRO RATA BASIS, AS DETERMINED BY THE DESIGNATED ORGANIZATION.

(b) THE DESIGNATED ORGANIZATION, ON BEHALF OF THE COUNCIL, MAY ACCEPT IN-KIND STAFF SUPPORT FROM NONPROFIT AGENCIES OR PRIVATE GROUPS OR MAY CONTRACT WITH NONPROFIT AGENCIES OR PRIVATE GROUPS FOR THE PURPOSE OF PROVIDING STAFF SUPPORT TO ASSIST THE COUNCIL IN CONDUCTING ITS DUTIES AND RESPONSIBILITIES. ANY STAFF SUPPORT PERSONNEL PROVIDED BY A NONPROFIT AGENCY OR PRIVATE GROUP, EITHER DONATED OR ENGAGED THROUGH A CONTRACT, SHALL NOT BE CONSIDERED EMPLOYEES OF THE COUNCIL OR THE DESIGNATED ORGANIZATION.

(c) THE DESIGNATED ORGANIZATION SHALL PREPARE AN OPERATING BUDGET FOR THE COUNCIL. PRIOR TO EXPENDING ANY OF THE MONEYS IT RECEIVES, THE COUNCIL SHALL TRANSMIT A COPY OF THE BUDGET TO THE PRESIDENT OF THE SENATE AND THE SPEAKER OF THE HOUSE OF REPRESENTATIVES AND SHALL CERTIFY THAT THERE IS ADEQUATE FUNDING AVAILABLE TO COVER THE EXPENSES OF THE COUNCIL AS IDENTIFIED IN THE BUDGET.

(2) (a) THERE IS HEREBY CREATED IN THE STATE TREASURY THE ALZHEIMER'S COORDINATING COUNCIL CASH FUND, WHICH SHALL ONLY CONSIST OF ANY MONEYS APPROPRIATED TO THE FUND BY THE GENERAL ASSEMBLY. MONEYS IN THE FUND SHALL BE SUBJECT TO ANNUAL APPROPRIATION BY THE GENERAL ASSEMBLY TO THE COUNCIL FOR THE PURPOSES SET FORTH IN THIS ARTICLE.

(b) ANY UNENCUMBERED OR UNEXPENDED MONEYS REMAINING IN THE FUND AT THE END OF ANY FISCAL YEAR SHALL REMAIN IN THE FUND AND SHALL NOT REVERT TO THE GENERAL FUND. IF, AT THE TIME THIS ARTICLE IS REPEALED PURSUANT TO SECTION 25-38-108, THE FUND CONTAINS A BALANCE OF UNENCUMBERED AND UNEXPENDED MONEYS, THOSE MONEYS SHALL REVERT TO THE GENERAL FUND.

25-38-108. Repeal of article. THIS ARTICLE IS REPEALED, EFFECTIVE JULY 1, 2012.

SECTION 2. Effective date. This act shall take effect at 12:01 a.m. on the day following the expiration of the ninety-day period after final adjournment of the general assembly that is allowed for submitting a referendum petition pursuant to article V, section 1 (3) of the state constitution, (August 6, 2008, if adjournment sine die is on May 7, 2008); except that, if a referendum petition is filed against this act or an item, section, or part of this act within such period, then the act, item, section, or part, if approved by the people, shall take effect on the date of the official declaration of the vote thereon by proclamation of the governor.

Peter C. Groff
PRESIDENT OF
THE SENATE

Andrew Romanoff
SPEAKER OF THE HOUSE
OF REPRESENTATIVES

Karen Goldman
SECRETARY OF
THE SENATE

Marilyn Eddins
CHIEF CLERK OF THE HOUSE
OF REPRESENTATIVES

APPROVED _____

Bill Ritter, Jr.
GOVERNOR OF THE STATE OF COLORADO

Table I. Personal Care Attendants, Home Health Aides, Certified Nursing Aides and Licensed Practical Nurses, 2009

	Educational requirements	Licensure	Dementia or Alzheimer's- specific training
Personal Care Attendants (PCA)	None/GED preferred	Certification is optional through the National Association for Home Care and Hospice (NAHC) for personal and home care aides. Not employed by a home care agency, but usually acts as an independent agent, employed by client directly or through an employment agency.	None
Home Health Aides (HHA)	None or same as CNA	None, or same as CNA, although beginning June 1, 2009, home care agencies that provide skilled nursing services must apply for licensure with the Colorado Department of Public Health and Environment, and home care placement agencies must notify the department in writing if they provide referrals for skilled home health services. As of January 1, 2010, home care agencies that provide in-home personal care must apply for licensure with the department; the State Board of Health must promulgate rules providing for minimum standards for operating agencies including inspections, educational requirements, enforcement remedies and annual license fees.	None
Certified Nursing Aides (CNA)	Nurse aide training programs must include a minimum of 75 hours of instruction, at least 16 of which must consist of supervised practical training. Supervised practical training is training in a clinical setting in which the trainee performs clinical tasks under the direct supervision of an RN or a licensed practical nurse (LPN).	Colorado has a Nurse Aide Practice Act that regulates the practice of CNAs with certification either by examination or endorsement. Certification within 4 months of obtaining employment as a nurse aide is required to practice in a nursing home or a home health agency. Certification is required prior to obtaining employment in a nursing pool or registry; there is no 4-month requirement to obtain the certification.	The Colorado Department of Regulatory Agencies (DORA) certifies CNAs and approves training curriculum which includes: mental health and social service needs, awareness of developmental tasks associated with the aging process, responding to behavior, allowing the resident to make personal choices, using the family as a resource, caring for cognitively impaired individuals including techniques for addressing the unique needs and behaviors of individuals with dementia, communicating with and understanding the behavior of cognitively impaired residents and responding appropriately to the behavior of cognitively impaired residents.

Table I. Personal Care Attendants, Home Health Aides, Certified Nursing Aides and Licensed Practical Nurses, 2009

	Educational requirements	Licensure	Dementia or Alzheimer's- specific training
Licensed Practical Nurses (LPN)	The LPN curriculum in Colorado is 9-11 months focusing on the care of patients with predictable outcomes. A high school diploma or its equivalent usually is required for entry, although some programs accept candidates without a diploma and some programs are part of a high school curriculum. The curriculum emphasizes the maintenance of patients and performance of nursing skills with a high degree of technical expertise. The LPN student is taught to identify normal from abnormal in each of the body systems and to identify changes in a patient's condition which are then referred to an RN or MD for a full assessment.	LPNs are required to pass a licensing examination, known as the NCLEX-PN, after completing a state-approved practical nursing program.	The National Federation of License Practical Nurses offers certification in gerontology, requiring an LPN license, copy of nursing school transcripts and a review of selected materials to qualify for examination. Must recertify every two years. The National Association for Practical Nurse Education and Service, Inc. also offers certification in long-term care (LTC), available to anyone who holds a current LP/VN license, documents 2,000 hours of long-term care practice within the previous 3 years and receives passing grade on the certification exam. Must recertify every three years.

Core competencies and best practice recommendations for direct care workers:

- Better Jobs Better Care—PA has designed the Universal Core Curriculum (UCC) for potential direct care workers to learn about positions in LTC settings and basic skills needed common to these settings. Consumers and workers report that it is the relationship that is at the heart of high-quality personal care. Students actively participate in their training through role-playing, small group work and demonstration of skills. Students' progress is measured by written tests and demonstration of interpersonal and direct care skills. The Universal Core Curriculum (UCC) requires approximately 60 hours of training while each module varies in terms of hours of training. The UCC requires the following modules specifically for Alzheimer's disease: recognizing symptoms of Alzheimer's disease and behavior changes; understanding the emotions of the patient with Alzheimer's disease; techniques to manage challenging behaviors related to dementia; relating to family members in respectful, professional manner; and understanding the role family members play in patient's care.
- The Iowa Alzheimer's disease state plan specifies these recommendations: minimum of 8 hours classroom instruction and 8 hours of supervised interactive experience for direct care workers; minimum of 8 hours annually of continuing education/in-service hours for direct care workers on the topic of Alzheimer's disease or related disorders; add a competency exam following Alzheimer's disease or related disorders training; establish a standard curriculum model that will include but not be limited to the diagnostic process, progression of the disease, communication skills (including the patient, family, friends and caregivers), family stress and challenges, nutrition and dining information, activities, daily life skills, caregiver stress, the importance of building relationships and understanding the personal history, expected challenging behaviors and non-pharmacologic interventions, and medication management; establish a certification process for trainers and educators of the standard curriculum model.

Table 2. Registered Nurses, Advanced Practice Nurses and Physician Assistants, 2009

	Educational requirements	Licensure	Dementia or Alzheimer's- specific training
Registered Nurses (RN)	There are 3 educational pathways to become an RN: bachelor of science in nursing (BSN), associate degree in nursing (ADN) and diploma. BSN programs are a 4-year degree; ADN programs take 2-3 years to complete; diploma programs are typically 3 years (diploma programs are very rare as more formal education is the preferred route to an RN license).	Students must graduate from an approved nursing program and pass a national licensing examination, known as the NCLEX-RN in order to obtain an RN license. Nurses may be licensed in more than one state, either by examination or by endorsement. Colorado is a member of the Nurse Licensure Compact Agreement which allows nurses licensed and permanently residing in a member state to practice in another member state without obtaining additional licensure. RNs can delegate within guidelines to an LPN, CNA or other health care professional, or an unlicensed person.	The Colorado Board of Nursing does not require Alzheimer's or dementia-specific training in RN programs. The RN program at the University of Colorado Denver (UCD) School of Nursing does introduce students to this material in a variety of courses in a minimal way.
Advanced Practice Nurses (APN)	All four advanced practice nursing specialties (nurse practitioners, certified registered nurse anesthetists, certified nurse midwives and clinical nurse specialists) require at least a master's degree. Most programs include 2 years of full-time study and require a BSN degree for entry; some programs require at least 1-2 years of clinical experience as an RN for admission.	Colorado statutes define an advanced practice nurse (APN) as a professional nurse who has acquired additional specialized education and training and is accepted by the Board of Nursing for inclusion in the advanced practice registry. Requirements for inclusion include the successful completion of a nationally accredited education program in the appropriate specialty and passing a national certification examination.	An APN can specialize in gerontology. To do so, an individual must hold a current RN license, 2 years of practice as an RN, have practiced 2,000 hours in a geriatrics setting in the last 3 years and have completed 30 hours of continuing education in the past 3 years. There are three specialty tracks: geriatric nurse specialist, clinical nurse specialist (CNS) in geriatric nursing or geriatric nurse practitioner. For the latter two, an RN must hold a master's, post-master's or doctorate degree from a geriatrics clinical nurse specialist program accredited by the Commission on Collegiate Nursing Education or the National League for Nursing Accrediting Commission. A minimum of 500 faculty supervised clinical hours must be included in the educational program.

Table 2. Registered Nurses, Advanced Practice Nurses and Physician Assistants, 2009

	Educational requirements	Licensure	Dementia or Alzheimer's- specific training
Physician Assistants (PA)	PA Training programs usually last at least 2 years and are full time. PA students complete more than 2,000 hours of supervised clinical practice prior to graduation. Most applicants to PA programs already have a bachelor's degree.	PAs must pass the Physician Assistant National Certifying Examination administered by the National Commission on Certification of Physician Assistants (NCCPA), which is open only to graduates of accredited PA education programs. Only those successfully completing the examination may use the credential Physician Assistant-Certified. To remain certified, PAs must complete 100 hours of continuing medical education every 2 years. Every 6 years, they must pass a recertification examination or complete an alternative program combining learning experiences and a take-home examination.	PA education includes classroom instruction in biochemistry, pathology, human anatomy, physiology, microbiology, clinical pharmacology, clinical medicine, geriatric and home health care, disease prevention and medical ethics. Students obtain supervised clinical training in several areas including family medicine, internal medicine, surgery, prenatal care and gynecology, geriatrics, emergency medicine, psychiatry and pediatrics. The rotations often lead to permanent employment. Accreditation standards require PA programs to provide clinical experience in LTC settings and require supervised clinical practice in geriatrics, including developmental psychology and end-of-life issues.

Core competencies and best practice recommendations for nursing:

- The American Association of Colleges of Nursing recommends these competencies for BSN curriculum: courses that address communication, group dynamics and psychiatric mental health, opportunities to address student attitudes and values about older adults and aging, strategies to maximize effective communication with older adults and issues of family dynamics as they apply to older adults. Students should be exposed to the cognitive changes common to older adults, particularly dementia, delirium and depression, and to case finding and management of elder mistreatment. Maximizing independence to maintain older adults in the least restrictive environment and alternatives to the use of physical and chemical restraints are recommended.
- The Geriatric Nursing Education Consortium has developed a set of core competencies for senior-level undergraduate nursing courses for dementia: assessing cognitive function using screening tools, such as the Folstein Mini-Mental State Examination or the Mini Cog, during various stages of dementia and in various clinical practice settings; assessing patients and caregiving situations for unsafe living conditions and making alternative plans of care; developing and co-managing dementia patients experiencing paranoia, delusions or hallucinations; recognizing risk for delirium associated with acute illness superimposed on dementia; identifying and modifying history taking and/or physical examination of older adults with aphasia from dementia; participating on interdisciplinary team; discussing with caregivers issues related to awareness of the impact of dementia on management of other medical conditions and behavioral management to optimize cognitive, functional and psychosocial well-being; evaluating cognitively impaired older adults experiencing pain, unsafe living conditions, frequent falling and/or urinary incontinence; recognizing stigma associated with cognitive impairment and interceding to counteract negative stereotypes in a selected clinical practice setting; and recommending care plans for older adults with early-moderate and late-stage dementia in various clinical practice settings.

Table 3. All Physicians and Geriatricians, 2009

	Educational requirements	Licensure	Dementia or Alzheimer's- specific training
All Physicians	Physicians typically complete a 4-year undergraduate degree, 4 years of medical school and 3-8 years of internship and residency (depending on the specialty selected). A few medical schools offer combined undergraduate and medical school programs that last 6 years rather than the customary 8 years.	To be licensed, physicians must graduate from an accredited medical school, pass a licensing examination and complete 1-7 years of graduate medical education. MDs and DOs seeking board certification in a specialty may spend up to 7 years in residency training, depending on the specialty. A final examination immediately after residency or after 1-2 years of practice also is necessary for certification by a member board of the American Board of Medical Specialists (ABMS) or the American Osteopathic Association (AOA).	There is no requirement to have a geriatric medicine rotation in Colorado. At UCD, medical students do have an obligatory internal medicine rotation and MAY get dementia exposure and usually a neurology rotation. All internal medicine residents at UCD have a 1-month obligatory geriatric medicine rotation and have considerable exposure to dementia in lectures, clinic, consults and nursing homes.
Geriatricians	After earning a medical degree, geriatricians complete a 3-year residency program in either internal medicine or family medicine before entering a geriatric medicine fellowship program.	Family physicians must be certified by the American Board of Family Medicine (ABFM) and must be diplomats in good standing in order to sit for a certificate of added qualification examination in Geriatric Medicine. Diplomats must hold a current, valid and unrestricted medical license, and must qualify by satisfactory completion of an Accreditation Council for Graduate Medical Education (ACGME) accredited fellowship training program in Geriatric Medicine. The American Board of Internal Medicine will grant credit for geriatric medicine training occurring in combination with a subspecialty of internal medicine consisting of: 1) 8 block months of geriatric medicine training; 2) the equivalent of 3 months training in continuing care (such as a continuity of care clinic); and (3) a one-month vacation or other leave.	Geriatricians develop clinical competence in the physiology of aging; illnesses common among older persons; atypical presentations of illnesses in older adults; the functional assessment of older adults; the treatment and management of older adults in acute care, LTC, community-based and home-care settings, and the assessment of cognitive status and mood in the elderly.

Table 3. All Physicians and Geriatricians, 2009

Core competencies and best practice recommendations for doctors:

- Competencies from the Association of American Medical Colleges and the John A. Hartford Foundation for cognitive and behavioral disorders include: 1) compare and contrast among clinical presentations of delirium, dementia and depression; 2) formulate differential diagnosis and implement initial evaluation in patient who exhibits delirium, dementia or depression; 3) in older patients with delirium, initiate urgent diagnostic work-up to determine the root cause (etiology); 4) perform and interpret cognitive assessment in older patients for whom there are concerns regarding memory or function; 5) develop evaluation and non-pharmacologic management plan for agitated demented or delirious patients.

Table 4. Licensed Clinical Social Workers, Psychologists and Licensed Professional Counselors, 2009

	Educational requirements	Licensure	Dementia or Alzheimer's- specific training	Core competencies and best practice recommendations
Licensed Clinical Social Workers (LCSW)	A master's degree in social work (MSW) is required to practice. A social worker may also receive a doctorate in social work (DSW) or a PhD.	Becoming an LCSW requires a master's degree in social work from a Council on Social Work Education (CSWE) approved program, passing the advanced generalist or clinical-level Association of Social Work Boards (ASWB) exam and completion of 2 years, 3,360 hours post-degree supervised experience with at least 96 hours of supervision (48 hours of which must be individual supervision). All candidates for social work licensure must also submit a completed, signed application, submit the appropriate fee and pass a board-developed jurisprudence examination. There is no specific certification available for geriatric social workers.	According to the John J. Hartford Foundation, most graduate social work students do not receive education or training in geriatrics or gerontology, much less in Alzheimer's or dementia. Many efforts are currently attempting to infuse geriatric content into social work curricula, including the Gero-Ed Center at the National Center for Gerontological Social Work Education. This center has developed Curriculum Development Institutes (CDIs), in which faculty participants will become leaders in preparing social work students with the knowledge, values and skills to meet the workforce needs of a rapidly aging society. Rather than adding specialization or electives to programs, the CDIs will infuse and transform foundational courses with gerontological competencies (e.g., a course about women in poverty would include a section on older women).	The CSWE, in collaboration with the National Center for Gerontological Social Work Education and Gero-Ed, has identified a list of foundational knowledge, values and competencies to form classroom learning objectives for bachelor of social work (BSW) and 1st year-MSW students. The list includes competencies such as: respect and promotion of older adults' rights to dignity and self-determination within the context of the law and safety concerns; using empathy and sensitive interviewing skills (e.g., reminiscence or life review, support groups, counseling); assessing social functioning (e.g., social skills, social activity level) and social support of older adults; assessing cognitive functioning and mental health needs of older adults (e.g., depression, dementia); and providing social work case management to link older adults and their families to resources and services and to conduct long-term planning.

Table 4. Licensed Clinical Social Workers, Psychologists and Licensed Professional Counselors, 2009

	Educational requirements	Licensure	Dementia or Alzheimer's- specific training	Core competencies and best practice recommendations
Psychologists	A doctoral degree usually is required for independent practice as a psychologist, which generally requires 5 to 7 years of graduate study.	In Colorado, the Examination for Professional Practice in Psychology is required, as well as post-doctoral experience adding to 1,500 hours of experience and 75 hours of supervision, 50 hours of which must be individual (face-to-face) supervision, all spread out over a minimum of 12 months. Post-doctoral supervised experience may not begin until the doctoral degree is conferred and applicants have obtained a counseling position with appropriate supervision.	For example, UCLA offers a two-year post-doctoral fellowship for psychologists which includes the following areas of training: phenomenology of mental health in older adults; psychiatric syndromes in older adults, cognitive disorders, psychosis, mood syndromes, anxiety, and others; age-related physiological changes affecting clinical phenomenology and pharmacotherapy; age-related psychosocial changes; neuropsychology and the healthy psychology of aging; community health issues and health service delivery research and administration.	<p>The American Association of Geriatric Psychiatry (AAGP) developed the "Geriatric Core Competencies for General Psychiatry Residents." The competencies outline the ability of residents to gather accurate key information from the patient, collateral sources, and other health care professionals as needed to complete:</p> <ul style="list-style-type: none"> * History * Mental Status Exam * Structured cognitive assessment (vascular, frontotemporal, Diffuse Lewey body dementia spectrum, Alzheimer's) * Functional assessment * Medical/Neurological Assessments * Abuse assessments * Caregiver issues * Community and home assessment <p>Other competencies include the recognition and management of risks, prevalence and presentation of cognitive disorders; recognition of the interplay between general medical conditions and psychiatric illness; use of effective listening and communication skills to accommodate sensory, cognitive and functional deficits of patients.</p>

Table 4. Licensed Clinical Social Workers, Psychologists and Licensed Professional Counselors, 2009

	Educational requirements	Licensure	Dementia or Alzheimer's- specific training	Core competencies and best practice recommendations
Licensed Professional Counselors	The Colorado Department of Regulatory Agencies (DORA) requires an LPC applicant to hold a masters or doctoral degree in professional counseling from a program approved by the Council for Accreditation of Counseling and Related Educational Programs or its equivalent as determined by the Board. Such degree or program must include a practicum or internship in the principles and the practice of professional counseling.	DORA also requires LPC applicants to have at least two years post degree experience (one year with a doctoral degree) under supervision approved by the Board (24 months, 2,000 hours of experience, with at least 100 hours of supervision, 70 hours of which must be individual supervision). Experience and supervision must be done concurrently over a minimum of 24 months and demonstrate professional competence by passing an examination in professional counseling as prescribed by the Board. Post-degree supervised experience may not begin until the degree is completed/conferred and the applicant has obtained a counseling position with appropriate supervision.	One example from the U.S. is at the University of Washington in Seattle. The school offers a Certificate in Geriatric Mental Health, for mental health counselors, social workers, and licensed psychologists. The certificate program includes the following areas of study: development of treatment plans; grief and loss related to aging; methods for accurately diagnosing dementia; psychiatric, medical, and pharmacological perspectives in the diagnosis and treatment of mood and thought disorders; and, effective ways to navigate multiple systems and community resources.	"Retooling the Health Care Workforce for an Aging America Act of 2009" was introduced both in the U.S. House and the Senate in January of 2009. The American Association of Geriatric Psychiatry worked with senators on provisions relating to mental health. AAGP supports a provision that would expand funding for Geriatric Education Centers (GECs) to include new grants for short-term intensive courses (mini-fellowships) in geriatrics, chronic care management and long-term care to faculty members of medical and other health professions school. It would require GECs applying for these grants to incorporate mental health and dementia "best practices" training into most of their courses.

Table 5. Physical Therapist, Occupational Therapist and Nursing Home Administrator, 2009

	Educational requirements	Licensure	Dementia or Alzheimer's- specific training	Core competencies and best practice recommendations
Physical Therapist (PT)	Individuals pursuing a career as a physical therapist usually need master's degree from an accredited physical therapy program. Only master's and doctoral degree programs are accredited in accordance with the Commission on Accreditation in Physical Therapy Education. Master's degree programs typically last 2 years and doctoral degree programs are 3 years.	Colorado requires the National Physical Therapy Examination for licensure.	The American Board of Physical Therapy Specialties has established minimum requirements to sit for the geriatrics specialist certification examination: 1) current license to practice physical therapy in the United States, 2) evidence of minimum of 2,000 hours of clinical practice in the specialty area, 25% of which must have occurred within the last 3 years; or 3) evidence of successful completion of a post-professional clinical residency that has a curriculum plan reflective of the "Description of Specialty Practice: Geriatric Physical Therapy."	According to new research reported at the Alzheimer's Association 2009 International Conference on Alzheimer's Disease, maintaining or increasing participation in moderate physical activity may help preserve memory and thinking abilities as individuals age. Benefits of regular exercise by people with Alzheimer's disease include maintenance of motor skills, decreased falls and reduced rate of disease associated with mental decline. Improved behavior and memory and better communication skills are a few other benefits associated with routine exercise programs for Alzheimer's disease patients.
Occupational Therapist (OT)	A master's degree or higher in occupational therapy is the minimum requirement for entry into the OT profession. OT programs also require the completion of 6 months of supervised fieldwork.	To obtain a license, applicants must graduate from an accredited educational program and pass the National Board for Certification of Occupational Therapy exam. Those who pass the exam are awarded the title "Occupational Therapist Registered (OTR)."	Board certification is offered for OTs in gerontology. Minimum requirements include: certified or licensed and in good standing with an American Occupational Therapy Association (AOTA) recognized credentialing or regulatory body, 2,000 hours of experience as an OT and 600 hours of experience delivering occupational therapy services in the certification area to clients (individuals, groups or populations) in the last 5 calendar years.	Occupational therapists may gain further training in various areas including driver rehabilitation. These occupational therapists have the skills to evaluate an individual's overall ability to operate a vehicle safely, and, where appropriate, to provide rehabilitation to strengthen skills used in driving.

Table 5. Physical Therapist, Occupational Therapist and Nursing Home Administrator, 2009

	Educational requirements	Licensure	Dementia or Alzheimer's- specific training	Core competencies and best practice recommendations
Nursing Home Administrator	A typical nursing home administrator has received a bachelor's degree in one of the following: business administration, public health administration, health administration, health care organizations and systems; or BSN or master's in LTC management. For Colorado, there is also a Nursing Home Administrator in Training requirement of 2,000 hours.	Both national and state exams are required for nursing home administrators. Nursing homes in the U.S. that provide Medicare and Medicaid services must operate under the supervision of licensed administrator. Every state requires that applicants for licensure pass the national licensing exam.	The National Association of Long Term Care Administrator Board does not specifically address Alzheimer's disease or dementia in its domains of practice.	<p>The Iowa State Alzheimer's Plan recommends broadening the spectrum of people who are required to receive training specific to Alzheimer's disease or related disorders to those who work in direct contact with people diagnosed with Alzheimer's disease, including but not limited to administrators, directors, dietary staff, administrative and management staff, hospital direct care staff, state employees with responsibility for LTC oversight/monitoring and ombudsmen. The national Alzheimer's Association offers these fundamentals for effective dementia care:</p> <ul style="list-style-type: none"> • Quality of life depends on the quality of the relationships they have with the direct care staff. • Optimal care occurs within a social environment that supports the development of healthy relationships. • Good dementia care involves assessment of a resident's abilities, care planning and provision, strategies for addressing behavioral and communication changes, appropriate staffing patterns and an environment that fosters community. • Each person with has a different constellation of abilities and need for support, which change over time as the disease progresses. • Staff can determine how best to serve each resident by knowing as much as possible about each resident's life story, preferences and abilities. • Develop "person-centered" strategies, which are designed to ensure that services are tailored to each individual's circumstances.

