

# Alaska's Roadmap to Address Alzheimer's Disease and Related Dementias

December 31, 2014



## Acknowledgments

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Alaska Commission on Aging

Alzheimer's Resource of Alaska

Alaska Mental Health Trust Authority

AARP

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Division of Senior and Disabilities Services

Division of Alaska Pioneer Homes

Division of Public Health

Division of Behavioral Health

Alaska Office of the Long Term Care Ombudsman

This study would not have been possible without funding from the Alaska Mental Health Trust Authority. Additionally, numerous stakeholders provided input through a day long workshop and a follow-up survey. They are listed in the second chapter of the Roadmap.

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# I. Executive Summary

## Alaska's Roadmap to Address Alzheimer's Disease and Related Dementias

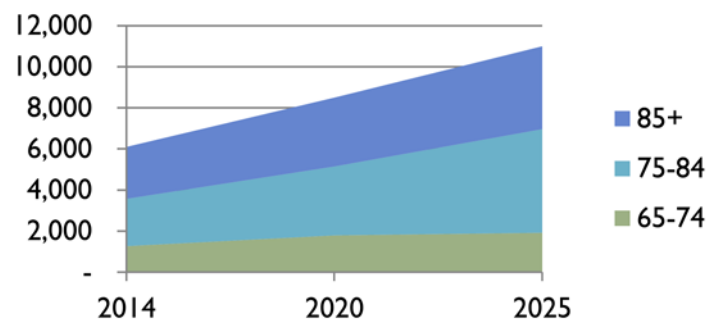
Alaska's Roadmap to Address Alzheimer's Disease and Related Dementias (ADRD) is a guide for prioritizing and implementing strategies that will improve the quality of life for Alaskans with ADRD and their caregivers. This Roadmap provides a comprehensive and coordinated approach to address the multiple and complex challenges that ADRD presents to individuals, families, caregivers and long-term care system in Alaska.

### Rationale for this Plan

The population of Alaskans with Alzheimer's disease will almost double in the next decade, from 6,100 in 2014 to 11,000 in 2025. This trend, illustrated in Figure 1, does not include younger onset or related dementias. While Alaska's senior population boom is driving much of this increase, risk factors for dementia such as stroke and chronic disease survivorship, mental health problems, and head injuries are also increasing. Using national indicators of these factors, a total estimate of ADRD in Alaska is approximately 8,000 in 2014, 11,000 in 2020 and over 14,000 in 2025.<sup>1</sup>

Alzheimer's disease rates increase from 3 percent of the population at ages 65 to 74, to 46 percent of the population age 85 and older. Stakeholders have pointed out gaps in the existing system of support services and residential options to serve individuals and caregivers, particularly as the number of people living with ADRD increases in the coming years.

FIGURE 1: ALASKA ALZHEIMER'S DISEASE PREVALENCE, AGES 65+, 2014-2025



Source: Alzheimer's Association, 2014 Alaska Alzheimer's Statistics.

### Process

The Alaska Commission on Aging (ACoA) initiated this effort with support from the Alaska Mental Health Trust Authority (The Trust) and Alzheimer's Resource of Alaska. The core team expanded to include a representative from AARP, the Alaska Department of Health and Social Services, Divisions of Senior and Disabilities Services, Public Health, Behavioral Health and the Alaska Pioneer Homes and the Office of Long Term Care Ombudsman. Using previous planning documents for guidance, including results from a

<sup>1</sup> Alzheimer's Association, Facts and Figures 2014

series of ACoA community forums, a caregiver survey and other states' ADRD plans, the core team drafted six goals each with a set of recommendations and strategies. The core team invited a broader group of stakeholders to review the draft document, identify priorities, and highlight opportunities for further collaboration. With stakeholder guidance, the core team selected seven strategies to work on in the near future; these are outlined in the Implementation Plan chapter at the end of the Roadmap.

## The Roadmap

### Vision

Alaska will identify Alzheimer's disease and related dementias as a public health priority due to the increasing number of Alaskans affected, and will build strong partnerships to address the challenges of this condition with safe and quality supports, from prevention and early detection, to end of life.

### Mission

To improve public awareness; promote prevention and early detection; increase access to necessary long-term services and supports; improve availability of safe, appropriate housing; and, increase caregiver supports for all Alaskans with Alzheimer's disease and related dementias.

### Document Purpose

The purpose of the Roadmap is to increase public awareness about ADRD, understand its current impact in Alaska, and to develop a comprehensive set of goals and strategies to address the impacts of this disease over the next five to ten years. The final chapter of the Roadmap outlines the near term strategies and convening organizations to begin implementation.

### Guiding principles

- Early detection and planning can vastly improve quality of life and ease the financial burden for individuals with ADRD and their caregivers.
- Individuals with ADRD should be able to reside in their homes and communities for as long as possible.
- While the incidence of ADRD increases in Alaska, it is important to address costs by providing services to people at the earliest stage possible and seek to serve people in the least restrictive and most appropriate care setting.

## Goals + Recommendations

The core team identified a set of goals and recommendations. The strategies for how to implement the recommendations are included in ranked order in the body of the Roadmap.

### Goal 1: Promote Public Awareness, Prevention and Early Diagnosis of Alzheimer's disease and Related Dementias.

Recommendation 1.1: Increase opportunities for public education about Alzheimer's disease and Related Dementias (ADRD).

Recommendation 1.2: Increase awareness of and access to ADRD resources.

Recommendation 1.3: Increase frequency of early screening and diagnosis.

Goal 2: Improve access to appropriate housing, services and supports for individuals with ADRD at all stages of the disease.

Recommendation 2.1: Develop service eligibility requirements based on functional, cognitive, and behavioral needs and reimbursement rates based on acuity levels.

Recommendation 2.2: Maintain individuals with ADRD in the least restrictive and most appropriate care setting possible.

Recommendation 2.3: Develop housing options for people with ADRD.

Recommendation 2.4: Identify the DHSS funding needs required to ensure access and to meet the needs of the rapidly growing population of those with ADRD in Alaska.

Recommendation 2.5: Optimize the role of the Pioneer Homes within the statewide array of long-term services and supports.

Recommendation 2.6: Increase access to end of life care.

Goal 3: Optimize quality, safety and efficiency of services to people with ADRD.

Recommendation 3.1: Ensure safety in private homes and communities for persons with ADRD.

Recommendation 3.2: Ensure safety and quality of care in residential settings.

Recommendation 3.3: Strengthen the role of the primary care setting as a point of entry to the dementia care system.

Goal 4: Develop a long-term care workforce trained in dementia care.

Recommendation 4.1: Increase the level of knowledge of dementia care and caregiver competence within the long-term services and supports workforce.

Recommendation 4.2: Ensure health, human service and public safety professionals are knowledgeable about dementia.

Recommendation 4.3: Increase cultural competence among dementia care workers.

Goal 5: Improve quality of life for family and other informal caregivers.

Recommendation 5.1: Maintain and improve the physical and mental health of family and other informal caregivers.

Recommendation 5.2: Develop a coalition of families and agency representatives to advocate for policy changes to support family and other informal caregivers and to decrease the financial burden of caregiving.

## Goal 6: Increase monitoring and research into ADRD prevalence, cost of care, prevention and treatment.

Recommendation 6.1: Maintain and expand research to understand ADRD prevalence, utilization and cost of care in Alaska.

Recommendation 6.2: Maintain and expand research of ADRD best practices related to risk reduction, treatment and care.

## Road Map Implementation

The core team will continue to meet to guide the implementation of the Roadmap. The implementation chapter identifies the core team agency or organization that will convene interested stakeholders to develop and implement the action plans for an initial set of seven strategies. These ADRD action workgroups will identify key milestones and timeframes, as well as performance measures to mark progress. The seven highest priority strategies are as follows:

1. Educate Alaskans about prevention, diagnosis, treatment, costs and appropriate care for people with ADRD through all possible media, in-person presentations, and policy advocacy. (1.1.1)
2. Assess feasibility and design an implementation plan for potential 1915 (i) and 1915 (k) HCBS State Medicaid Plan amendments. (2.1.1)
3. Identify the DHSS resources needed through 2025 and 2035 to ensure those with ADRD can remain living safely in their own home or family caregiver's home for as long as possible. (2.4.1)
4. Develop and implement regulations for quality standards for assisted living homes and other residential settings so that caregivers' skills are appropriate to the population they serve. (3.2.1)
5. Increase dementia care training across the continuum of care and in complementary fields such as police, emergency services, finance, justice system, nursing, dental, optometry, social work and mental health. (4.2.1)
6. Increase training to caregivers about ADRD, resources available and approaches and strategies for providing care and reducing stress and fatigue. (5.1.1)
7. Increase in-home respite and adult day services to meet caregiver needs for appropriate breaks in providing care. (5.1.2)



# 2. Roadmap Development

## History

In 2011, the Alaska Commission on Aging (ACoA) with support from The Trust, Alzheimer's Resource of Alaska, and the Alaska Department of Health and Social Services, Senior and Disabilities Services (DHSS SDS) started the Roadmap project in response to concern expressed by stakeholders. Family and other informal caregivers and senior service providers have long identified the need for dementia-focused long-term support services for Alaskans with Alzheimer's disease and related dementias (ADRD), including health care providers who understand Alzheimer's disease and improved supports and training for caregivers. Cueing and supervision are services especially needed to support persons with dementia living independently.

In 2012 and 2013, the ACoA conducted seven ADRD community forums statewide and a survey of caregivers caring for family members with ADRD. The DHSS Division of Public Health (DHSS PH) and ACoA partnered successfully together to obtain funding from the National Association of Chronic Disease Directors to include a set of ten questions about cognitive impairment in the 2013 Behavioral Risk Factor Surveillance Survey. The BRFSS survey findings have provided for the first time state-level, population-based data on cognitive impairment, Alzheimer's disease, dementia, and the status of family and other unpaid caregivers taking care of loved ones with these conditions. In 2014, the National Alzheimer's Association published projected estimates at the state level of individuals aged 65 and older with Alzheimer's disease.

## Previous Planning

### Alaska

Other planning efforts in Alaska have recognized the increase in the senior population and the potential impact of Alzheimer's disease and related dementias on families, communities and the State. These efforts included:

- Alaska's Long-term Services + Supports: Recommendations for a Strategic Plan (DHSS, 2013)
- Proposed Plan for Implementing Community First Choice in Alaska (DHSS, 2012)
- Alaska State Plan for Senior Services, FY 2012-2015 (ACOA)
- Alaskans At Risk Of Out Of State Placement Due To Complex Behavior Management Needs (WICHE Mental Health Program, July 2009)

"Alaska's Long-term Services + Supports: Recommendations for a Strategic Plan" included a recommendation to "maintain individuals with ADRD in the least restrictive and most appropriate care setting," with a strategy to create an Alaska ADRD State Plan. Identified now as "Alaska's Roadmap to Address ADRD," this document serves as a companion document specific to ADRD and references many of the concepts and recommendations outlined in the 2013 LTSS Recommendations. The former DHSS Commissioner's vision for LTSS is "a sustainable long-term care delivery system that ensures the right care is delivered at the right time to the right person for the right cost." ADRD planning and the type of care system it recommends works toward this same vision.

Long-term services and supports exist as part of a continuum of care for seniors and people with disabilities, with the goal of maintaining the level of independence desired by individual and family. Investments in prevention and caregiver support services at the lower end of the continuum can increase quality of life and independence while containing cost of care for individuals and the State. To achieve this goal of service delivery to the appropriate level of care, the LTSS Recommendations include rate revision to incentivize providers to take on individuals with more complex needs, such as those with ADRD. Reviewing reimbursement rates is also addressed in Goal 2 of the Roadmap. Other elements that are outlined in both documents, but made more specific to ADRD in the Roadmap, include improving awareness of existing resources, optimizing the role of the Pioneer Homes and increasing the quality and quantity of the paid workforce.

### National and Other States

The National Alzheimer's Project Act of 2011 called for an integrated national plan to overcome Alzheimer's disease. The Act served to coordinate Alzheimer's disease research and services across all federal agencies and accelerate the development of treatments that would prevent, halt, or reverse the course of Alzheimer's disease. While the intention of national planning focuses more on research and treatment, there is also a goal to improve early diagnosis and coordination of care and treatment of Alzheimer's disease, improve outcomes for ethnic and racial minority populations that are at higher risk for Alzheimer's disease, and coordinate with international bodies to fight Alzheimer's globally.<sup>2</sup> The U.S. Department of Health and Human Services oversees The National Alzheimer's Plan, which resulted from the 2011 Act, and includes the following five goals:

- Prevent and effectively treat Alzheimer's disease by 2025
- Enhance care quality and efficiency
- Expand supports for people with Alzheimer's disease and their families
- Enhance public awareness and engagement
- Improve data to track progress

The nationally-based Advisory Council on Alzheimer's Research, Care, and Services updates actions for the goals and strategies of the Plan every year. The National Alzheimer's Association encourages, coordinates and supports state-level planning to achieve the national goals. Thirty six states have published Alzheimer's disease state plans to comprehensively address the impact of Alzheimer's, and seven, including Alaska's, are in progress. State-level planning is important because Medicaid, a primary funder of long term services and supports, is administered by state governments. The National Alzheimer's Association produced a comparison of ADRD State plans across common topic areas. The Roadmap includes Alaska specific strategies and funding opportunities for many of the themes and recommendations identified in other state level planning.

### **Core Team + Stakeholder Guidance**

In early 2014, The Trust provided the services of its contractor, Agnew::Beck Consulting, to facilitate the development of the Roadmap. A core team guided the project including:

- Denise Daniello, Alaska Commission on Aging
- Karl Garber, Alzheimer's Resource of Alaska

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<sup>2</sup> National Alzheimer's Project Act, 2011, Public Law 111-375

- Amanda Lofgren and Nancy Burke, Alaska Mental Health Trust Authority
- Ken Helander, AARP
- Duane Mayes and Lisa Morley, Senior and Disabilities Services
- Ken Truitt and Vickie Wilson, Alaska Pioneer Homes
- Jean Findley, Public Health
- Al Wall and Reta Sullivan, Behavioral Health
- Diana Weber and Teresa Holt, Office of Long Term Care Ombudsman

The core team met twelve times during 2013 and 2014. Using existing planning documents, data from the State of Alaska and National Alzheimer's Association, results from the ACoA community forums and caregiver survey and other ADRD plans for guidance, the core team drafted six goals with recommendations, strategies, lead organizations and performance measures to reach those goals. In May of 2014, the ACoA and Alzheimer's Resource of Alaska presented the initial findings and broad goals at the Alaska 'Power of Aging' Symposium. In October 2014, the core team invited a broader group of stakeholders to review the draft Roadmap and highlight opportunities for change or further collaboration. The core team presented specific strategies and facilitated small group work sessions around each goal. The core team revised the strategies using input from the workshop and presented them again at Alzheimer's Resource of Alaska's 'Vision to Reality' Conference in November 2014. After finalizing the comprehensive list of strategies for the Roadmap, the core team conducted a survey of stakeholders to identify priority strategies and who would like to be involved in implementation. The ranked strategies are presented in order of importance in the Roadmap. The core team then identified seven strategies for near term implementation from strategies that were ranked first or second in the survey. These top seven strategies are outlined in the implementation chapter.



*The Core Team presents at Alzheimer's Resource of Alaska's Vision to Reality Conference in 2014*

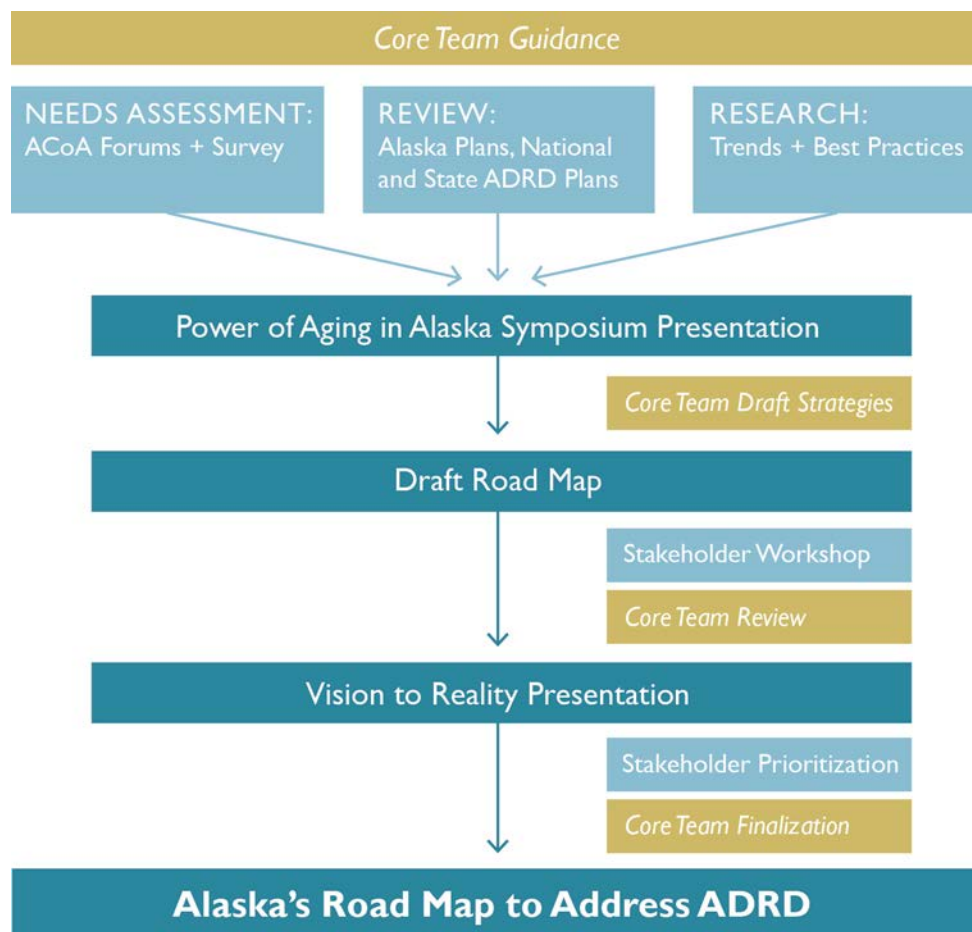
The stakeholders involved in the development of the Roadmap include:

- |  |                                       |
|--|---------------------------------------|
| • Alaska Native Tribal Health Consortium                     | • Gretchen Keiser                     |
| • Alaska Housing Finance Corporation                         | • Fairbanks Resource Agency           |
| • Alaska Primary Care Association                            | • Fireweed Place                      |
| • Alaska State Hospital and Nursing Home Association         | • Haines Assisted Living              |
| • Bristol Bay Area Health Corporation/<br>Kanakanak Hospital | • Dr. Janelle Kam- Magruder           |
| • Statewide Independent Living Council of Alaska             | • Juneau Commission on Aging          |
| • Anchorage Senior Activity Center                           | • Kathleen Strasbaugh                 |
| • Central Council Tlingit & Haida Indian Tribes of Alaska    | • Leiza Johnson                       |
| • Governor's Council on Disabilities and Special Education   | • Margaret Sharpe, Alaska Legislature |
|  | • Marilyn McKay                       |
|  | • Mat-Su Health Foundation            |
|  | • Marlow Manor Assisted Living        |
|  | • Municipality of Anchorage           |
|  | • Mountain-Pacific Quality Health     |

- Native Village of Unalakleet
- Representative Paul Seaton, Alaska State Legislature
- ResCare Alaska
- Retired Public Employees of Alaska
- Sandra Heffern
- Senior Citizens of Kodiak, Inc.
- Representative Shelley Hughes, Alaska Legislature
- Sitka Pioneers' Home
- Southeast Senior Services
- Tanana Chiefs Conference
- University of Alaska
- Unalakleet IRA Elders Services
- Wildflower Court
- Yukon Koyukuk Elder Assisted Living Facility

These organizations and individuals are also listed in the implementation chapter, along with other likely stakeholders and advocates who could be resources for implementing the Roadmap.

FIGURE 2: ADRD ROADMAP PROCESS



# 3. Alzheimer's Disease and Related Dementia in Alaska

## What is ADRD?

Alzheimer's disease is the most common form of dementia, caused by the death of brain cells and the atrophy of the brain.<sup>3</sup> Other common related dementias include vascular, mixed dementia, Parkinson's, and Lewy Body dementia. Alzheimer's occurs in 60 to 80 percent of dementia cases.<sup>4</sup> As neurons are damaged and die, the person suffers cognitive impairment and the symptoms associated with Alzheimer's disease. Symptoms typically associated with ADRD include loss of memory and language ability, loss of balance and thinking abilities and changes in personality and behavior.

While there is no known prevention, cure or mechanism to slow progression, there are identified age, genetic and environmental risk factors. Most people with Alzheimer's disease are diagnosed at age 65 or older. Although age is a significant risk factor, Alzheimer's disease is not a normal part of aging and advanced age alone is not sufficient to cause the disease. Research also points to other risk factors such as cardiovascular disease, family history, traumatic brain injury, uncontrolled diabetes, prolonged depression, hearing loss, Down's syndrome, social isolation, and lower socioeconomic status, which, in general, may increase personal risk for disease and restrict access to medical care.

## Younger Onset ADRD

Alzheimer's disease and related dementias most commonly affect people over the age of 65, although approximately four percent of diagnoses are in younger people aged 30-64.<sup>5</sup> Younger onset ADRD poses additional challenges to families, because the individual is more likely to be a primary breadwinner and/or caregiver in a family with dependents compared to individuals with later onset ADRD.

Additionally, it is more difficult to diagnose ADRD in younger onset individuals due to its relative rarity. Furthermore, there is lack of awareness about eligibility for financial support from the Social Security Administration and other sources. Younger onset individuals can use Social Security Disability Insurance and Supplemental Security Income as part of the "compassionate allowance initiative." Eight percent of Alaska Medicaid recipients with ADRD are under the age of 65.<sup>6</sup>

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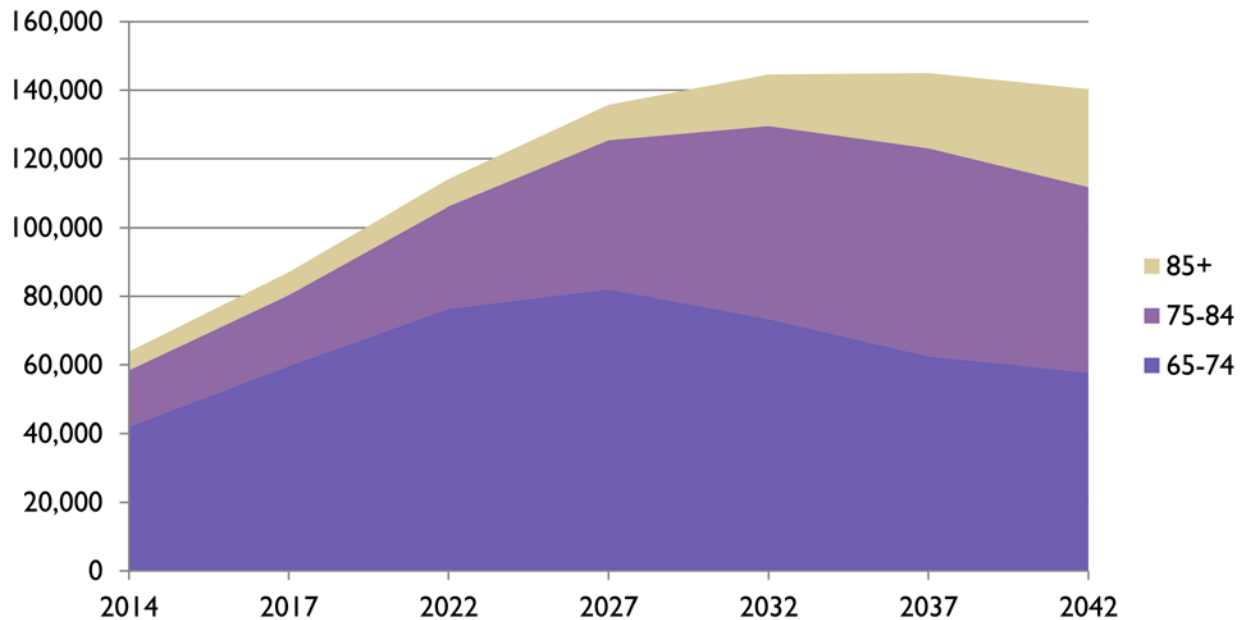
<sup>3</sup> Alzheimer's involves the "accumulation of the protein fragment beta-amyloid (plaques) outside neurons in the brain and twisted strands of the protein tau (tangles) inside neurons." (Alzheimers.org)

<sup>4</sup> Alzheimer's Association, 2014 Facts and Figures

<sup>5</sup> Alzheimer's Association, 2012 letter on younger onset

<sup>6</sup> Alaska Department of Health and Social Service, 2014

FIGURE 3: PROJECTED ALASKA SENIOR POPULATION 2014-2042



Source: Alaska Population Projections 2012 to 2042, Department of Labor and Workforce Development, State of Alaska, 2014

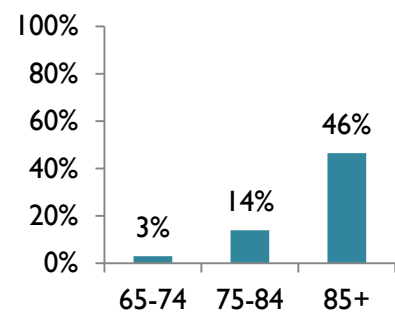
## Senior Population Boom in Alaska

The projected percent increase in Alaska seniors is the greatest in the nation. Figure 3 shows this impending wave. The population aged 85+ grows an average of 15 percent annually over the next forty years. Alzheimer's disease is becoming a major public health issue that can no longer be ignored. Due to the changing demographics in Alaska, we can expect an increase in the number of people at risk for developing Alzheimer's disease. Alaska's older adult population is booming, and advanced age is the greatest risk factor for Alzheimer's disease.

## ADRD Prevalence in Alaska

The National Alzheimer's Association models the projected number of seniors 65 and older who have Alzheimer's disease. An estimated 9 percent of Alaska seniors 65 and older have Alzheimer's disease. Alzheimer's disease rates increase with age (See figure 4). ADRD directly affects almost half of Alaskans over 85, and around 24 percent of Alaska Adults Living Independently (ALI) Medicaid waiver recipients.<sup>7</sup> The projected number of individuals over age 65 with Alzheimer's will grow from 6,100 in 2014 to 11,000 in 2025. These projections, shown in Figure 5, do not include persons with related dementias and those younger than 65.

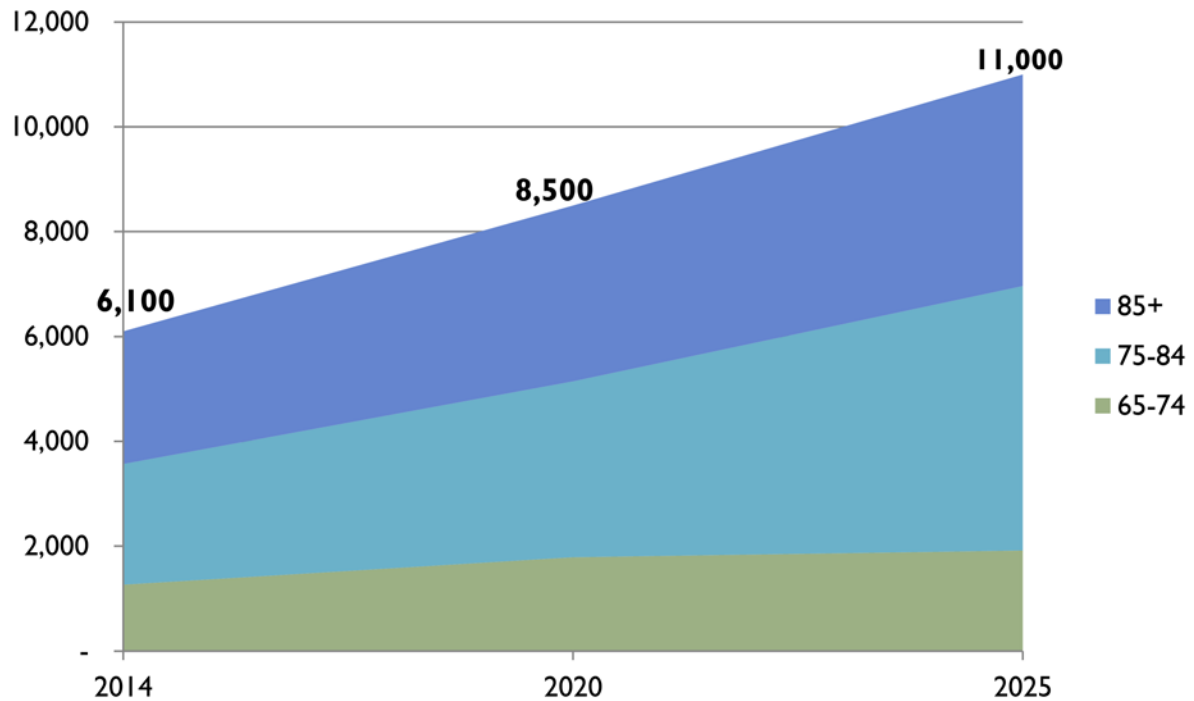
FIGURE 4: ALASKA ALZHEIMER'S DISEASE RATES, BY AGE



Source: Alzheimer's Association, 2014 Alaska Alzheimer's Statistics

<sup>7</sup> State of Alaska DHSS SDS Data Transmittal 7/4/2014

FIGURE 5: ALASKA ALZHEIMER'S DISEASE PREVALENCE, AGES 65+, 2014-2025



Source: Alzheimer's Association, 2014 Alaska Alzheimer's Statistics.

Risk factors for dementia such as stroke and chronic disease survivorship, mental health problems, and head injuries are also increasing. Teepa Snow, a national dementia care and training specialist, highlights the following concerns related to these risk factors:

- People over the age of 80 to 85 have a higher possibility of mixed picture dementia when Alzheimer's disease is combined with a second form of dementia such as vascular or fronto-temporal dementia, or alcohol-related dementia.
- More people are surviving strokes, heart attacks, congestive heart failure, chronic obstructive pulmonary disease, diabetes, and other chronic health conditions that predispose them to various forms of dementia at a higher rate and at younger ages. Having poorly managed diabetes or hypertension increases the risk of dementia by 50-77 percent according to several recent studies.
- Mental health problems increase risk for dementia by about 50 percent compared to peers without those conditions.
- Head injury increases risk of fronto-temporal dementia within 5-20 years by about 50 percent.
- Fronto-temporal dementias are the most common for those younger than 65 and people born with Down syndrome tend to develop dementia at a very high rate and experience the symptoms in the age range of 35 to 65 years of age due to premature aging.



Using national indicators of these factors, a total estimate of ADRD in Alaska is 8,000 in 2014, 11,000 in 2020 and 14,300 in 2025.<sup>8</sup> Due to the prevalence of head injuries, Down's syndrome and mental health challenges in Alaska, these numbers are likely an underestimate.

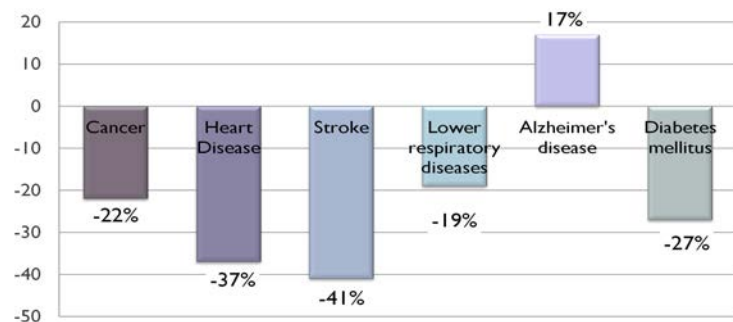
Alzheimer's disease is also one of the few major causes of death that is increasing in Alaska. Between 2000 and 2011, deaths due to Alzheimer's increased 17 percent, whereas heart disease, cancer and stroke have decreased by more than 20 percent (Figure 6). ADRD may be a factor in more deaths than reported due to co-occurring symptoms and disorders. People 65 and older survive from four to eight years after diagnosis, but some live up to 20 years.

### Perceived Cognitive Impairment

The Division of Public Health and ACoA partnered successfully in 2013 to obtain funding from the National Association of Chronic Disease Directors to include a set of 10 questions about cognitive impairment in the Behavioral Risk Factor Surveillance Survey (BRFSS) of 2013.

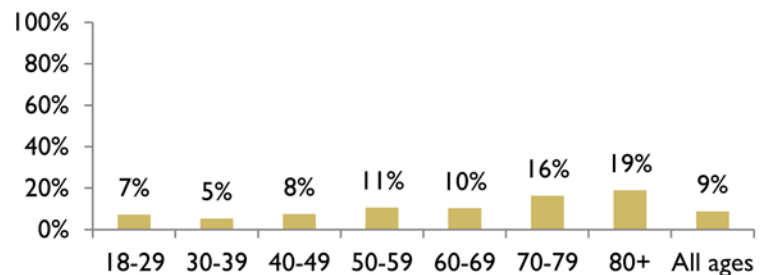
One of the questions asked respondents, "During the past 12 months, have you experienced confusion or memory loss that is happening more often or is getting worse?" This experience is summarized as "perceived cognitive impairment." While this definition of memory loss is more expansive than Alzheimer's disease or other dementias, it provides data on the

FIGURE 6: PERCENTAGE CHANGE IN SELECTED CAUSES OF DEATH IN ALASKA, 2000-2011



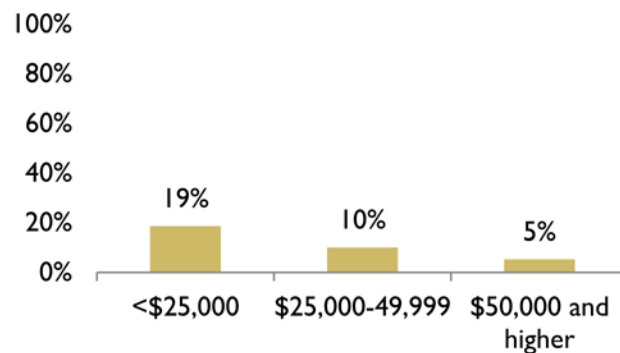
Source: Alaska Bureau of Vital Statistics 2000 & 2011

FIGURE 7: PERCENT OF POPULATION WITH PCI BY AGE CATEGORY



Source: Alaska 2013 Behavioral Risk Factor Surveillance Survey

FIGURE 8: PERCENT OF POPULATION WITH PCI BY INCOME CATEGORY



Source: Alaska 2013 Behavioral Risk Factor Surveillance Survey

<sup>8</sup> Alzheimer's Association, 2014 Facts and Figures



possible relationships between memory loss and other health indicators, how memory loss affects Alaskans' lives, and if and how they access care.

An estimated nine percent of Alaskans experience perceived cognitive impairment (PCI), with higher rates occurring in older populations. PCI occurs more often in populations with lower incomes. An estimated nineteen percent of Alaskans with income under \$25,000 experience PCI versus five percent of Alaskan with incomes greater than \$50,000.

PCI occurs more frequently in populations that have poor health indicators. For example, among respondents to the 2013 BRFSS survey, 14 percent of smokers in Alaska reported PCI compared with seven percent of nonsmokers. Additionally, 22 percent of people reporting a depression diagnosis at any point in their life also report PCI. Among respondents reporting two or more chronic conditions such as cardiovascular disease, high

blood pressure, high cholesterol, diabetes, asthma, or arthritis, 12 percent reported PCI compared with six percent of respondents who reported no chronic health conditions. Among the subset of respondents who report that they experience PCI, 88 percent report that they experience two or more chronic health conditions.

These trends apply to general health status as well. Among respondents that describe their health as fair or poor, 27 percent report PCI, compared with only four percent of Alaskans who describe their health as excellent.

FIGURE 9: PERCENT OF POPULATION WITH PCI BY HEALTH CONDITIONS

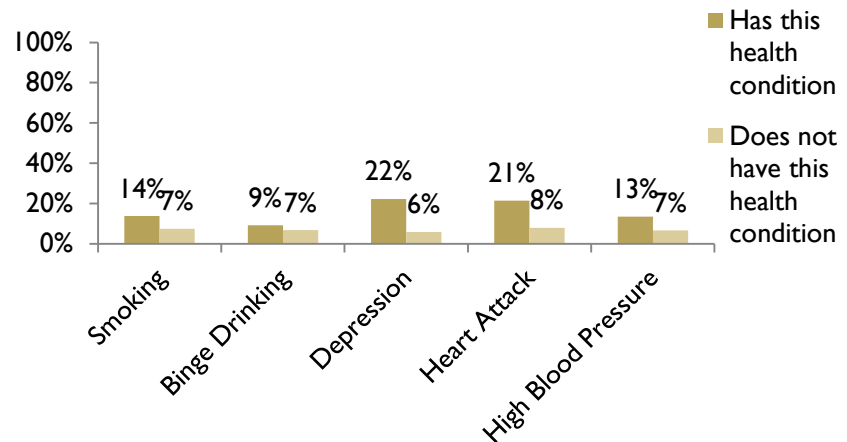


FIGURE 10: PCI AND CHRONIC CONDITIONS

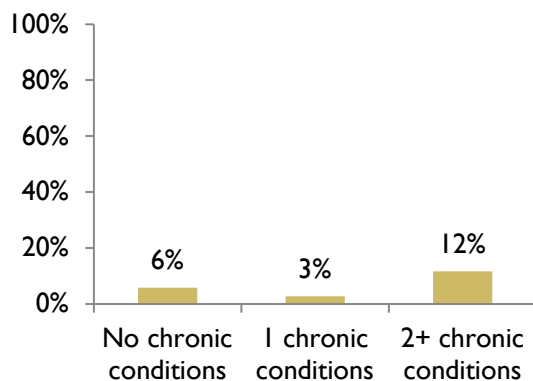


FIGURE 11: PCI AND GENERAL HEALTH STATUS

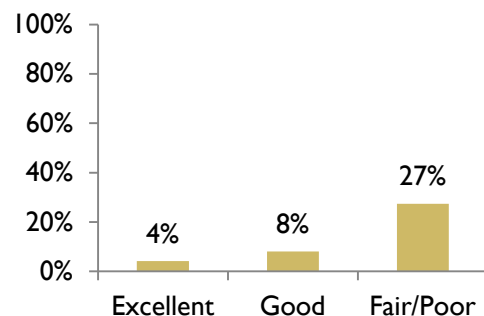


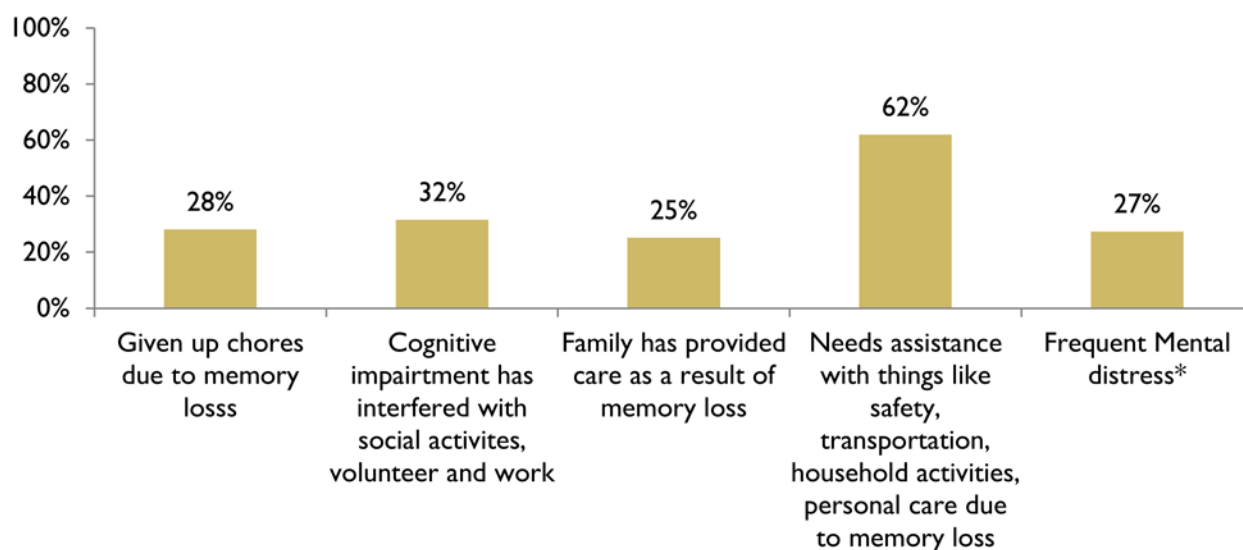
Fig. 9-11 Sources: Alaska 2013 Behavioral Risk Factor Surveillance Survey

## Impacts to Daily Life

The Behavioral Risk Factor Surveillance Survey also asks about the impacts to daily life for individuals with PCI and their families and communities. When asked about the effect of memory loss on regular activities, 29 percent of respondents with PCI said they had given up chores or other household tasks due to memory loss, and PCI had interfered with 32 percent of respondents' social activities, volunteer commitments or work. Sixty-two percent of respondents said they needed assistance with things like safety, transportation, household activities, and personal care due to memory loss. Twenty-five percent of respondents said that their family had provided care to them as a result of memory loss.<sup>9</sup>

The Alaska Commission on Aging (ACoA) conducted community forums and caregiver surveys to gain a more nuanced understanding of the impact of ADRD on Alaskans.

FIGURE 12: IMPACTS TO DAILY LIFE AS A RESULT OF PCI



\* Frequent mental distress was not reported specifically related to memory loss. (Source: Alaska 2013 Behavioral Risk Factor Surveillance Survey)

<sup>9</sup> Due to small sample sizes, response categories around impacts due to PCI were collapsed into "sometimes to always" and "rarely to never".

## Community Forums

The ACoA held seven community forums in 2012 and 2013 to understand the needs of individuals with Alzheimer's disease and their caregivers. Key findings included:

- Lack of public awareness and misunderstanding about Alzheimer's disease and related dementia
- Inadequate services for people with ADRD
- Unpaid caregivers are often stressed and unprepared
- Acute need for safe and appropriate housing for seniors with ADRD and those with challenging behaviors
- Critical need to improve safety for persons with ADRD

TABLE 1: CAREGIVER COMMUNITY FORUMS, 2012-2013

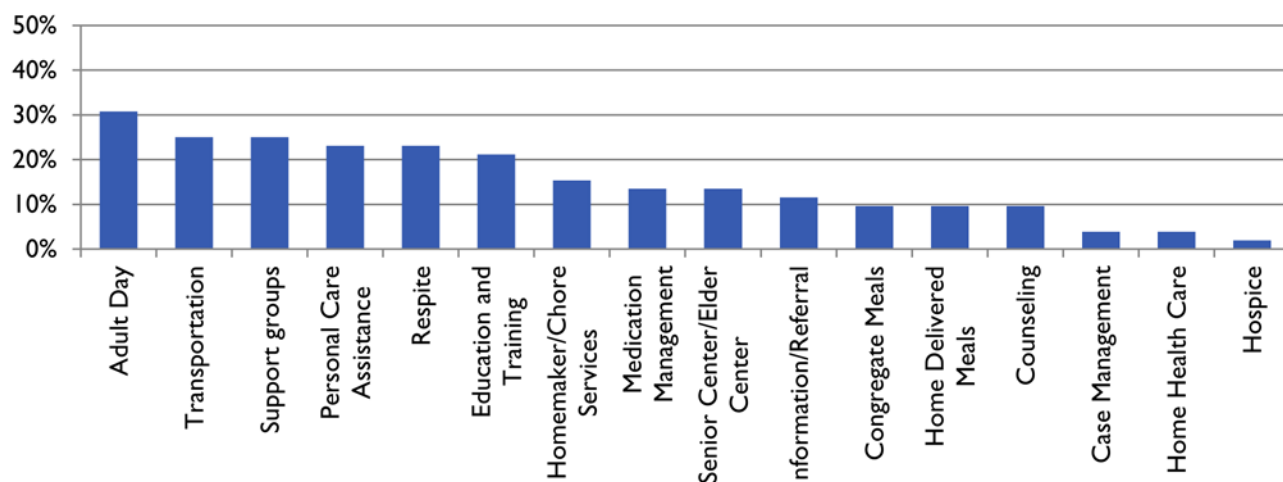
Forum Location	Participants
Anchorage	50
Juneau	15
Fairbanks	32
Homer	18
Soldotna	28
Kodiak	12
Mat-Su, Palmer	6
<b>Total</b>	<b>161</b>

## Caregiver Survey

The ACoA survey of family and other informal caregivers received 52 responses.<sup>10</sup> The responses indicate that Alaska caregiver characteristics are similar to those across the nation. The majority of caregiving for persons with ADRD is provided by caregivers who are not paid, most commonly immediate family members.

Dementia caregiving tasks include help with instrumental activities of daily living, activities of daily living, medication management, coordinating care, medical appointments, managing behavioral symptoms, supervision, and coordinating decision-making with other family members regarding care plans. Caregiver respondents to the ACoA survey provide an average of 15 hours of care per day, 47 weeks per year for an average of 3.9 years. Sixty percent of the ADRD recipients live with their caregiver. Figure 13 indicates that 31 percent of caregivers use adult day care, 25 percent use transportation and support groups and 23 percent use personal care assistance and respite services.

FIGURE 13: WHICH SUPPORT SERVICES DO YOU OR THE PERSON YOU CARE FOR USE?

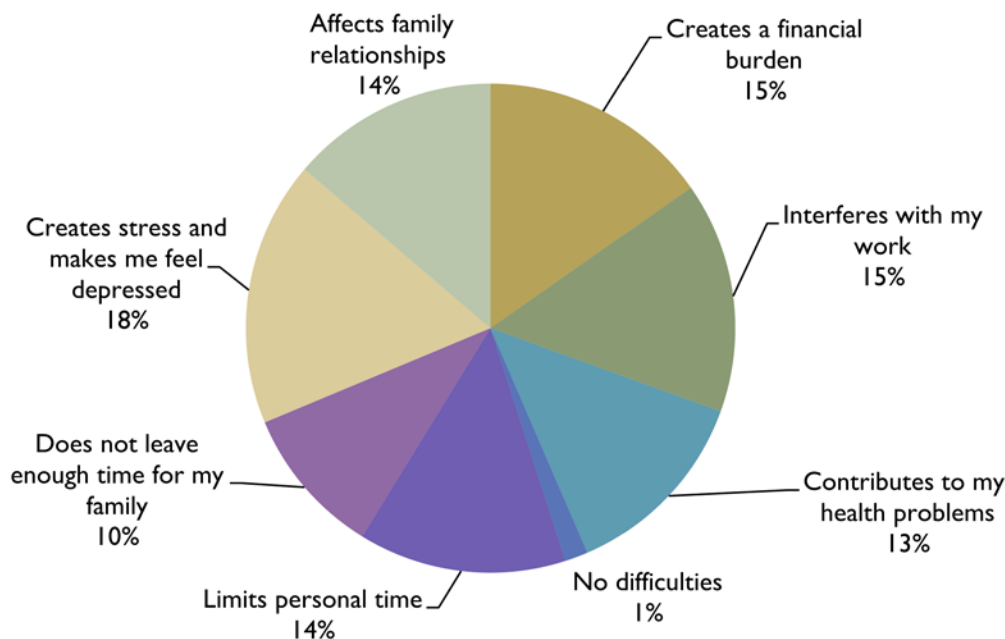


Source: ACoA Caregiver Survey

<sup>10</sup> Survey respondents were 62% women, 23% age 65+, 50% have some college education, 70% are married or in a long-term relationship.

As Figure 14 shows, there is no single dominant challenge faced by all caregivers; rather caregivers face a variety of pressures from financial to personal health and family functioning.<sup>11</sup> These results indicate that any policy or programs directed at supporting caregivers should address these multiple pressures. Caregivers do take advantage of programs.

FIGURE 14: WHAT IS THE MOST DIFFICULT CHALLENGE YOU FACE AS A CAREGIVER?



Source: ACoA Caregiver Survey

## Cost of Care

### Caregivers

The cost of caregiver support programs are a fraction of replacing the dollar value cost of unpaid caregiving. The National Alzheimer's Association produces an annual estimate of the value of caregiving for each state. In 2013, 33 thousand Alaska caregivers provided 37 million hours of care valued at \$466 million. The cost of healthcare for caregivers in Alaska in 2012 was \$26 million higher than for Alaskans who are not caregivers.<sup>12</sup>

<sup>11</sup> Respondents were asked to rank the issues from one to nine – this is the distribution of the top answers.

<sup>12</sup> Alzheimer's Association, 2014 Alaska Alzheimer's Statistics

## Care Facilities

In 2014, there were 266 assisted living homes licensed for 2,389 beds for seniors in Alaska, including seniors with mental or physical disabilities. While there are not firm numbers on the number of memory care beds, the Pioneer Home does provide dedicated ADRD units in five of its six locations throughout the state, totaling 99 units of capacity or 4.1 percent of all beds.<sup>13</sup>

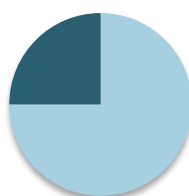
This is slightly lower than the United States average of 4.4 percent of beds dedicated to dementia care.<sup>14</sup> In 2014, there were 599 skilled nursing beds in Alaska with 36 beds designated for dementia care.<sup>15</sup> Given the projected 15 percent average annual increase in seniors over age 85, the highest risk age group for ADRD, many communities in Alaska are preparing for an increased demand for assisted living, skilled nursing and dementia specific beds. Nationally, people with Alzheimer's disease age 80 and older are more than 18 times more likely to be admitted to a nursing home than the general population above age 80. People with dementia are twice as likely to die in a nursing home as the general population.<sup>16</sup>

TABLE 2: ADRD DESIGNATED UNITS IN THE PIONEER HOME SYSTEM

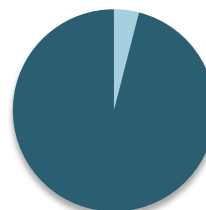
Location	Units
Anchorage	38
Sitka	21
Fairbanks	16
Palmer	14
Ketchikan	10
<b>System Total ADRD Dedicated Capacity</b>	99
<b>Total Licensed Capacity</b>	499

FIGURE 15: NATIONWIDE USE OF CARE FACILITIES

**Nursing home admission age 80+**

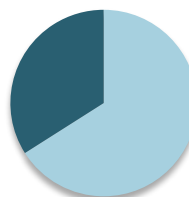


75% of people with Alzheimer's

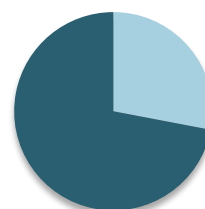


4% of the general population

**Die in a nursing home**



67% of people with dementia



28% of the general population

Source: Alzheimer's Association, 2014 Facts and Figures

<sup>13</sup> Sitka has an additional 12 spaces in a delayed egress wing that are not specifically designated as ADRD but the home accepts up to an additional 6 ADRD residents there. Juneau does not have a dedicated delayed egress ADRD wing or neighborhood but has one of the highest resident censuses of people diagnosed with ADRD. Ken Truitt, Alaska Pioneer Homes.

<sup>14</sup> Adapted from Alzheimer's Association, 2014 Facts and Figures based on 2013 data from the American Health Care Association

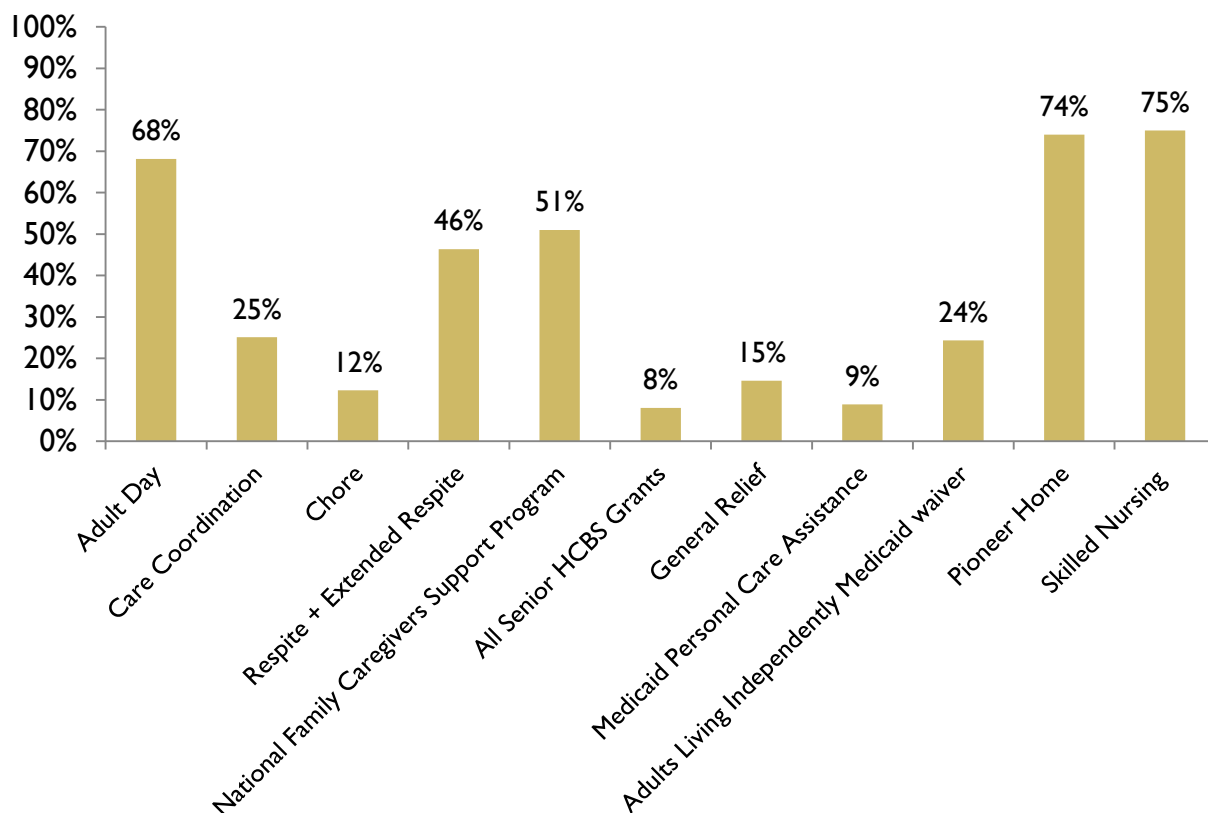
<sup>15</sup> Dennis Murray, Alaska State Hospital and Nursing Home Association, October 22, 2014.

<sup>16</sup> Alzheimer's Association, 2014 Facts and Figures

## State Programs

The State of Alaska administers programs across the continuum of care to support seniors and individuals with Alzheimer's disease and related dementia. The State is only one payer for long-term care services. Other sources include private pay, such as long-term care insurance, savings or paying out of pocket. As mentioned earlier, caregivers also provide unpaid care. It is difficult to determine the total costs of long-term care for people with ADRD because of the complexity of the payment and support systems.<sup>17</sup>

FIGURE 16: ADRD PREVALENCE IN STATE PROGRAMS



Source: SAMS (Home and Community Based Services programs ADRD rates); DHSS 7/2014 (Medicaid and General Relief rates); Pioneer Home 7/2014 (Pioneer Home ADRD rates); Dennis Murray, ASHNHA, October 22, 2014.

<sup>17</sup> A recent request for proposals for a performance review of the DHSS long-term care system explains the difficulty of knowing exact utilization rates and, by extension, the diagnosis that would accompany them: "Individuals receiving long term care services may be eligible for and utilize more than one service managed through the department. With this in mind, it is difficult to identify exactly how many individuals are receiving services and the cost of services provided to each eligible individual. This is an area where coordination of care may be unclear. DHSS lacks a system for tracking and monitoring utilization of services." Information is available for individual programs, but it is difficult to un-duplicate utilization of the state system as whole.

## Utilization

The State funds grantee organizations to provide senior in-home services including care coordination, chore, respite and extended respite that extend the time that people with ADRD are able to remain in their own homes. State financed adult day programs also allow seniors to stay in their homes longer by providing caregivers with a safe, structured environment for seniors during the day. The National Family Caregivers Support Program, funded by the federal government and administered by the State, also supports caregivers caring for seniors in the community. The State contracts with grantees to provide nutrition, transportation and support services such as congregant and home delivered meals, taxi vouchers, senior rides, homemaker, legal assistance, information and assistance, and nutrition education.

Individuals with ADRD make up varying percentages of total individuals served by home and community based services. Sixty-eight percent of individuals in adult day programs have ADRD. Caregivers can support individuals with ADRD in their own homes but often need time during the day to go to work, do household chores or take care of themselves or other family obligations. Respite programs also serve a high percent of individuals with ADRD, at 46 percent of recipients.

The Medicaid waiver program allows people who qualify for nursing home level of care, but who have higher income levels than are allowed to qualify for regular Medicaid, to be eligible for Medicaid funding to be supported in their home or a community-based facility. The majority of seniors and individuals with ADRD on the Medicaid waiver program qualify for the Adults Living Independently waiver, which serves 749 individuals with ADRD, or 24 percent of all ALI waiver recipients.<sup>18</sup>

Medicaid also funds personal care assistance (PCA) services to individuals for assistance with the activities of daily living, like bathing and feeding. Fifteen percent or 146 individuals served by Medicaid PCA have an ADRD diagnosis. This lower percentage likely reflects that many individuals are able to complete activities of daily living, but they need cueing to remember to do so. Under current regulations, they might qualify for PCA services or the Medicaid waiver program, although only if they have other functional impairments in addition to the need for cueing. Other states have adopted a state Medicaid plan amendment to waive standard Medicaid eligibility requirements for those with dementia. The purpose of this waiver, entitled 1915(i), is to allow dementia patients to receive Medicaid support for help with cueing and supervision, even while they are able to still physically perform activities of daily living.

The State-funded Alaska Pioneer Homes are located in six communities across the state. Over the last twenty years, the Pioneer Homes have transitioned from providing an equal balance of senior housing and assisted living supports, to offering primarily higher levels of assisted living. In particular, the assisted living focuses on dementia care. Seventy-four percent, or 338, of the Pioneer Homes' residents have an ADRD diagnosis. Seventy-five percent, or 449, of the residents in Alaska skilled nursing facilities have an ADRD diagnosis.<sup>19</sup>

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<sup>18</sup> To be eligible for the ALI waiver, the senior must be under a specified income level and meet Nursing Facility Level of Care (NFLOC) requirements. Nursing Facility Level of Care is a technical term defined in Alaska statute (see 7AAC130.215. level-of-care determination) as well as through the State's published training curriculum for care coordinators and it sets the eligibility criteria for the Medicaid waiver program. An individual applying for a Medicaid waiver receives an assessment by the State of Alaska and if it is determined that the individual experiences significant limitations in bed mobility, eating, locomotion (moving around), transfer (getting from one surface to another), dressing, and toileting they may meet NFLOC requirements and may qualify for the Medicaid waiver. If both income and NFLOC conditions are met, the individual may receive care through the Medicaid waiver either in their home or in an assisted living home.

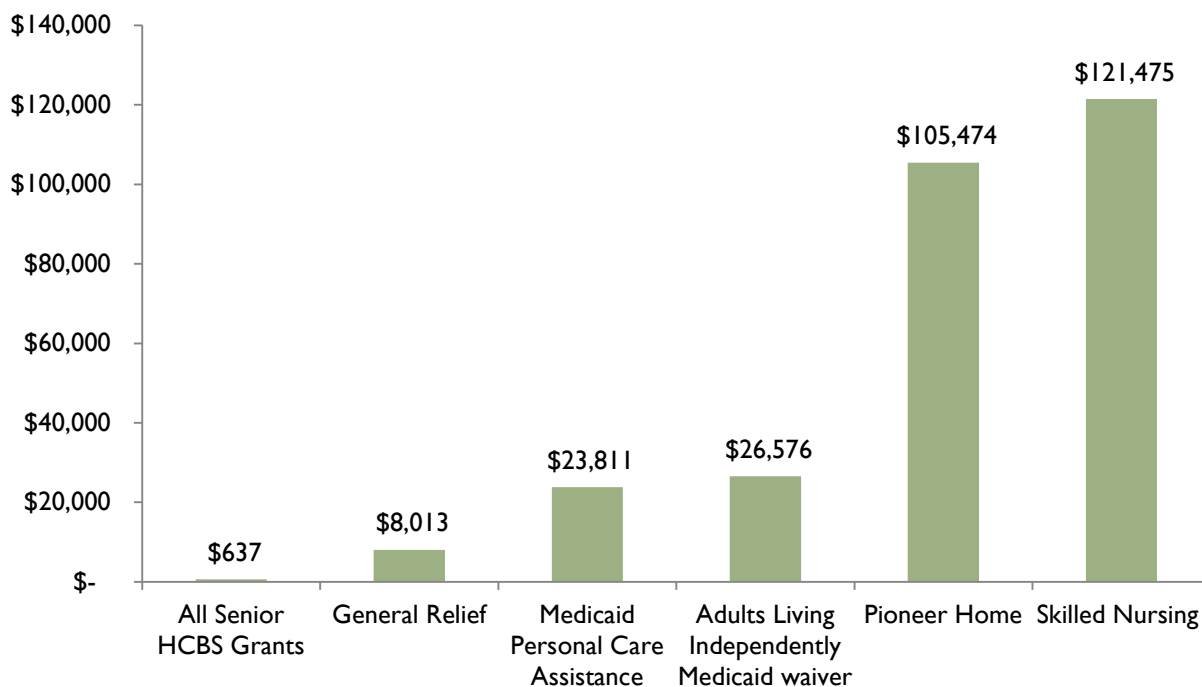
<sup>19</sup> Dennis Murray, ASHNHA, October 22, 2014.

## Cost

Due to the complexity of cost, funding, eligibility, duration of services, duplication and patient privacy, it is difficult to compare the exact cost per recipient for all State programs. However, the relative costs are accurate and help develop an understanding of what programs tend to be less expensive and which are more expensive. The estimated average cost per recipient for various State programs are shown in Figure 17. These costs include all sources, such as the federal share of Medicaid that is reimbursed to the State, as well as any private pay, particularly for the Pioneer Home. The State data do not show the higher cost for serving those with ADRD. However, it is assumed that it is more resource intensive to serve individuals with ADRD, due to complex behaviors and the need for supervision.

Supporting individuals in their homes with PCA services costs around \$20,000 per year per individual. Medicaid waiver services provide care to individuals in their home and in licensed assisted living facilities including the Pioneer Home. The Alaskans Living Independently (ALI) waiver has an average cost of approximately \$25,000 per person. The Pioneer Home costs around \$100,000 per individual, which includes the amount individuals contribute through private pay. Additionally, the Pioneer Home operates a program called Payment Assistance, which helps offset the costs to Pioneer Home recipients who do not have adequate income or assets to pay the full cost. The Pioneer Home also accepts Medicaid. The average cost per recipient of those at skilled nursing facilities on Medicaid is about \$121,000. This does not include those who pay with private resources to be in skilled nursing facilities.

FIGURE 17: AVERAGE COST PER RECIPIENT OF STATE PROGRAMS



*Source: Counts of recipients and costs of programs from Fiscal Year 2015 State Budget. There is some overlap with the federal Nutrition, Transportation and Support grants, which do not track ADRD diagnosis or duplication of services, costing approximately \$575/pp (DHSS 9.2.14). Pioneer Home costs include management, but are offset by private pay and Medicaid reimbursement. Federal dollars reimburse the state for half the costs of Medicaid programs, which include waiver programs in home and community based settings, including the Pioneer Home. Skilled nursing cost are from a presentation by SDS from April 2014 and do not include private pay.*



# 4. Goals, Recommendations and Strategies

The following chapter provides the recommendations and strategies, as well the rationale and potential fiscal implications for each of the following six goals:

**Goal 1. Promote Public Awareness, Prevention and Early Diagnosis of Alzheimer's disease and Related Dementias.**

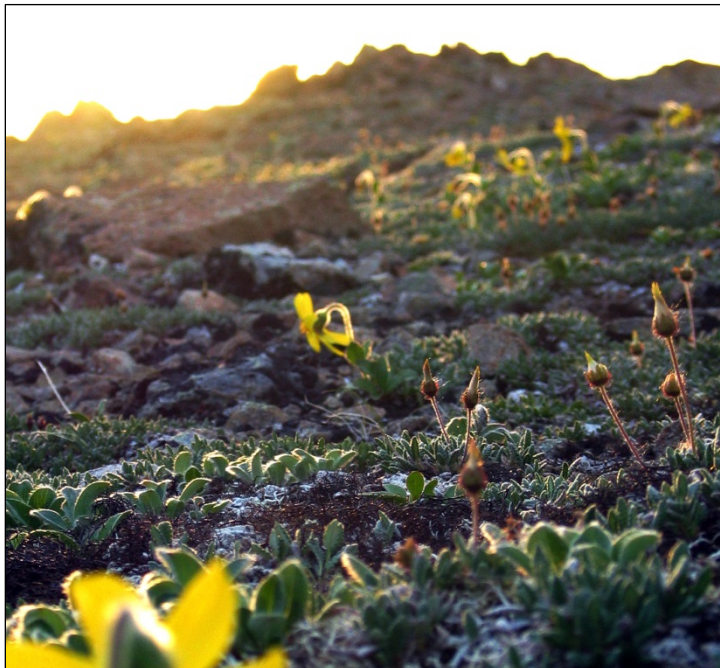
**Goal 2. Improve access to appropriate housing, services and supports for individuals with ADRD at all stages of the disease.**

**Goal 3. Optimize quality, safety and efficiency of services to people with ADRD.**

**Goal 4: Develop a long-term services and supports workforce trained in dementia care.**

**Goal 5. Improve quality of life for family and other informal caregivers.**

**Goal 6. Increase monitoring and research into ADRD prevalence, cost of care, prevention and treatment.**



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# Goal 1. Promote Public Awareness, Prevention and Early Diagnosis of Alzheimer's disease and Related Dementias.

## Rationale

**ADRD still carries a stigma that prevents people from seeking the resources and assistance they need.** This may delay diagnosis and treatment, and cause social isolation and depression. In order to reduce this stigma and empower people affected by ADRD, the public needs to better understand the disease and know how to seek appropriate medical care and supportive resources. Education and outreach to youth about ADRD can also help foster respect and appreciation of individuals with ADRD across the lifespan.

When a person is concerned about possible symptoms of ADRD, it is important that he or she connect with the most appropriate resources with in-depth knowledge of the disease and the continuum of care. Aging and Disability Resource Centers are valuable existing resources for people seeking information about aging. If staff at Aging and Disability Resource Centers are educated about the resources available to address ADRD, early diagnosis could increase, and allow people with ADRD and their caregivers to better plan for medical and support needs.

**There is an opportunity for physicians to more routinely screen for memory loss.** Detecting and diagnosing Alzheimer's disease can be a difficult and challenging experience. Patients with symptoms of Alzheimer's disease often have limited capacity to recognize their symptoms and often attribute them to aging or chronic illness.

**Early diagnosis can help individuals and families prepare financially and emotionally for the changes that result from ADRD.** It also allows family to learn how they can help and how to cope. Such efforts result in people being able to live safely in their own homes for a longer time, sometimes at a lower cost, with improved quality of life.

## Fiscal Implications

Cost impacts for strategies need to be evaluated. Early diagnosis may result in lower health care costs due to lower health care utilization and fewer emergency health care events.

## **Recommendation 1.1: Increase opportunities for public education about Alzheimer’s disease and Related Dementias (ADRD).**

### Strategies

1. Educate Alaskans about prevention, diagnosis, treatment, costs and appropriate care for people with ADRD through all possible media, in-person presentations, and policy advocacy.
2. Encourage wellness across the lifespan through prevention and risk reduction activities that improve brain health such as the “Healthy Body, Healthy Brain” initiative that includes helping people understand the connection between risk and protective factors and cognitive health.
3. Continuously educate individuals and families about planning for Power of Attorney, wills and guardianships, planning for their futures and paying for long-term care, and being prepared for steps in the disease process.
4. Assemble content for easily shared and integrated publicity campaigns and outreach through social media, as a portal for people seeking information about resources and to raise awareness. Promote and integrate existing resource library into campaigns. Materials and strategies can be linked to other public health and wellness messages.
5. Distribute relevant, targeted materials for people across ethnicities, languages, ages and geographies.
6. Identify and build nontraditional partnerships to increase awareness, including an increased presence at community events and non-medical settings.
7. Help support peer groups to identify and encourage people to speak out about their experience and reduce stigma.

## **Recommendation 1.2: Increase awareness of and access to ADRD resources.**

### Strategies

1. Ensure there is “no-wrong door” to access ADRD resources across various media, diagnostic settings and government agencies.
2. Use and improve the existing network of Aging and Disability Resource Centers to increase referrals to Alzheimer's Resource of Alaska, senior centers and other community resources.
3. Engage hospital and skilled nursing facility social workers, case managers and discharge planners to increase referrals to the Alzheimer's Resource of Alaska and other community resources.
4. Engage Alaska’s Federally Qualified Health Centers to increase referrals to the Alzheimer's Resource Agency and other community resources.

## **Recommendation 1.3: Increase frequency of early screening and diagnosis.**

### Strategies

1. Develop multi-disciplinary teams to provide peer professional education and outreach to physicians and other providers to recognize and address early signs of dementia.
2. Increase the use of dementia screenings and tracking cognitive changes compared to baseline at annual exams for individuals over age 60 in primary care settings.
3. Create a “tool box” for persons with diagnosis of ADRD to encourage early screening and diagnosis.

# Goal 2. Improve access to appropriate housing, services and supports for individuals with ADRD at all stages of the disease.

## Rationale

**Access to needed supports will be challenging as the population is expected to rapidly grow.** The population with Alzheimer's disease in Alaska is estimated at 6,100 people and the total population with ADRD is estimated at 8,000 people in 2014. This is projected to grow to over 14,000 by 2025, an approximately seven percent annual growth rate. This population will continue to grow rapidly through 2035. It is imperative to have excellent stewardship of resources that promote the highest access, quality and cost savings for services to people with ADRD.

The former DHSS Commissioner's vision for Alaska's system of long term services and supports is "a sustainable long-term care delivery system that ensures the right care is delivered at the right time to the right person for the right cost." The State's current rate structure for long-term services and supports does not provide a reimbursement rate for services to individuals with higher physical, cognitive or behavioral needs based on their functional need. There is little incentive to providers to develop the additional capacity required to care for these higher-needs individuals, including those in the end stages of Alzheimer's disease.

**People often prefer to remain living safely in their homes** for as long as possible. This results in improved health, quality of life and is the lowest cost model. Adult day care and respite programs provide community-based services that engage individuals and provide respite to family caregivers to delay placement in institutional placements.

**People will sometimes need out of home placement** as the disease progresses to ensure their health and safety. There is an increasing demand statewide for senior housing options, including assisted living, to allow elders to age in their communities. Currently, there are limited specialized memory care units and assisted living homes with sufficiently trained staff to provide optimal care for people with ADRD. Many facilities are not equipped to provide care to residents with high needs due to dementia. For example, dementia care patients might need more supervision if they have a tendency to wander. The lack of appropriate beds sometimes results in individuals being placed at API or in skilled nursing facilities when they could be cared for in less restrictive settings if they were available.

Currently, if an individual is presenting difficult behaviors, there is not an obvious mechanism in place to use the Complex Behavior Collaborative or other resources to prevent placement into a more restrictive setting. The Complex Behavior Collaborative provides technical resources to agencies and providers of care to people with complex needs, such as aggressive behavior.

**The Pioneer Home serves the higher end of the continuum of care.** In spite of more than 500 people on the active waitlist and over 9,000 people on the inactive waitlist, some of the Pioneer Homes have vacant beds because they are not staffed to meet the needs of more than a specific number of high needs residents. The use of Level 1 beds has decreased as people are able to access home and community-based services and remain in their own homes for longer. It may be feasible for DHSS to establish a public-private partnership to operate a “home within a home” so that currently vacant beds in the Pioneer Home can be utilized for older Alaskans with ADRD.

**Access to resources can also be limited by the eligibility criteria of funding sources.** An individual with ADRD who requires assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) may not meet the nursing facility level of care (NFLOC) required for the current Medicaid 1915 (c) waiver program. She or he may be functionally able to perform tasks but require prompting and cueing to know when to perform daily tasks. Other states have allowed individuals who require verbal prompting and cueing to perform tasks by amending the State Medicaid Plan to include a 1915 (i) home and community-based service option that does not require that a person meets NFLOC criteria. Implementing a 1915 (i) will prevent some individuals with ADRD from being placed in inappropriate care settings such as the Alaska Psychiatric Institute or a skilled nursing facility, as sometimes occurs currently. It would also provide a more appropriate funding source for individuals who require assistance than the State’s General Relief. Individuals are often then placed into assisted living homes under the State’s General Relief Assisted Living Program. This increases the use of the State’s General Relief program because individuals with ADRD placed in assisted living facilities are not able to move into a lower care setting. The General Relief program is intended for emergency and temporary placement, but often is extended because other payment sources are not available. 1915(i) can also include a family caregiver assessment to determine ability and resources. 1915 (k) option does require a person to meet Nursing Facility Level of Care but provides an additional six percent federal reimbursement for PCA services. The study for 1915(k) has been completed by Home and Community Based Strategies (2010).

**End-of-life care, including hospice, is an unmet need across the state.** Hospice can increase quality of life at the end of life for people with ADRD and their caregivers. Elders living in both rural and urban areas often want to spend their remaining days at home and in their own communities surrounded by family and friends where the people, food, and language are familiar. Hospice provides the older person with the means to die with dignity in the comfort of their own home or in a home-like environment where only palliative care is provided. Long term care facilities are not currently required to have end of life policies and procedures in place. Their focus is on providing care to the ADRD patient by following doctors’ orders or plans of care. However, family members are sometimes unfamiliar with the end of life process for a loved one with ADRD. Family members, patients and facilities are better served when they are helped to identify and articulate their personal spiritual and philosophical concerns and desires in the dying process.

### Fiscal Implications

Implementing the 1915(i) and (k) State Plan amendments could reduce costs per individual with ADRD by preventing higher level medical costs from more intensive care settings. However, serving more people at

lower levels of care could also increase costs to the State. The fiscal impacts of implementing the 1915(i) and (k) options are complex and need to be assessed. This will identify the total resources needed due to the rapidly growing population of those with ADRD in Alaska and the savings that would be generated by improving the care delivery system.

Increased costs to establish hospice services in rural Alaska may be offset by not having to transport rural Elders to higher cost care in urban settings. Hospice can provide a cost savings by keeping people out of the hospital or skilled nursing facility at the end-of-life and in their own homes and communities.

## **Recommendation 2.1: Develop service eligibility requirements based on functional, cognitive, and behavioral needs and reimbursement rates based on acuity levels.**

### Strategies

1. Assess feasibility and design an implementation plan for a potential 1915 (i) and 1915 (k) HCBS State Medicaid Plan amendments.
2. Increase services in rural areas through tribal and other partnerships to provide home and community based services such as PCA and assisted living, and skilled nursing. Assess demand for and supply of services for each region and encourage coordination to maximize efficient service delivery.
3. Implement a payment system that sets reimbursement rates based on acuity levels to incentivize providers to offer specialized dementia care, increase training to their staff and meet higher quality standards.
4. Establish and define levels of acuity based on both functional and behavioral needs.

## **Recommendation 2.2: Maintain individuals with ADRD in the least restrictive and most appropriate care setting possible.**

### Strategies

1. Ensure the appropriate use of skilled nursing facilities for persons with ADRD by increasing specialized memory care beds that provide both appropriate environments and trained staff to serve people with ADRD.
2. Increase capacity for adult day and respite services.
3. Eliminate unnecessary admissions to Alaska Psychiatric Institute (API) through increased utilization of the Complex Behavioral Collaborative (CBC) for people with ADRD.

## **Recommendation 2.3: Develop additional housing options for people with ADRD.**

### Strategies

1. Identify need for additional community skilled nursing beds specific to ADRD.
2. Incentivize public - private partnerships to develop assisted living and memory care units.
3. Ensure adequate availability of assisted living options within statewide array of long-term services and supports.

4. Incentivize the development of crisis respite beds that are short-term specialized treatment settings to serve people with challenging and aggressive behaviors within other care settings to help stabilize difficult behaviors and allow people to return to lower level care settings.
5. Pilot small scale supported housing in rural areas that can be adapted to meet the need of the community and be financially sustainable, such as multi-use supported housing and assisted living co-located with independent senior housing.
6. Identify and publicize funding mechanisms for developing assisted living and memory care units.

## **Recommendation 2.4: Identify the DHSS funding needs required to ensure access and to meet the needs of the rapidly growing population of those with ADRD in Alaska.**

### Strategies

1. Identify the DHSS resources needed through 2025 and 2035 to ensure those with ADRD can remain living safely in their own home or family caregiver's home for as long as possible.
2. Identify the DHSS resources needed through 2025 and 2035 to ensure those with ADRD have access to out of home services as needed.

## **Recommendation 2.5: Optimize the role of the Pioneer Homes within the statewide array of long-term services and supports.**

### Strategies

1. Assess the current and future capacity of the Pioneer Home to determine how it can be leveraged to address the gaps in services for people with ADRD.
2. Evaluate the current Pioneer Home wait list process and determine whether an approach that triages the wait list by level of care can more effectively serve those with ADRD.
3. Educate the public and providers about the role of Pioneer Homes in providing care to people with ADRD including the Memory Care neighborhoods within the Pioneer Homes, the care model provided to all residents and the availability of care.
4. Examine the use of the payment assistance program for those individuals who could qualify for the Medicaid waiver in order to maximize the value of State General Funds.

## **Recommendation 2.6: Increase access to end of life care.**

### Strategies

1. Expand availability of, and reimbursement for, hospice and palliative care in both rural and urban areas.
2. Educate the public and health care providers about hospice and end of life care.
3. Increase use of hospice, palliative and end of life care within assisted living and skilled nursing facilities.
4. Increase access to anticipatory grief training and bereavement support for individuals and their families.



# Goal 3. Optimize quality, safety and efficiency of services to people with ADRD.

## Rationale

**Participants in ADRD community forums expressed concern that knowledge of the disease, as well as best practices in care, vary significantly between settings,** which affects the quality of care for people with dementia. Centers for Medicare and Medicaid Services has developed and distributed to all nursing homes a training program to make caregivers more proficient in working with residents who have dementia. State assisted living licensing regulations do not currently require specialized dementia care training for homes licensed to serve adults with disabilities.

The responsibility for monitoring the safety of ADRD patients in facilities rests on several state agencies. Adult Protective Services, the Office of the Long term Care Ombudsman, Residential Licensing workers and Health Care Facilities surveyors all conduct investigations in response to complaints. Licensing conducts regular inspections of homes to ensure regulatory compliance. In addition, the Office of the Long Term Care Ombudsman has the legal authority to conduct unannounced visits to facilities for the purpose of resolving residents' complaints and advocating for the protection of residents' rights. The demand for ombudsman advocacy has grown rapidly, though capacity is limited owing to small staff, limited funds and the challenge of recruiting volunteer ombudsmen statewide.

**Safety and quality is important in the home setting as well.** Many people desire to remain in their homes as they grow older. Home modifications remove structural barriers that can make it difficult for older adults and people with physical and cognitive limitations to navigate in the home and can increase safety and accessibility. HomeMAP is a "best practice" in home modifications that involves a home assessment that identifies immediate and possible future concerns and challenges through observation and interviews with the resident and family members. Contractors or others can use the final reports from the assessment to complete needed modifications. The Home MAP tool can also identify assistive technology to maximize independence. Smart Home technologies increase safety and accessibility in the home by using a variety of sensors such as sound, movement and temperature, to monitor a person's daily activities to ensure safety. These technologies also can provide prompts when needed to remind the person to turn off the stove, take medication, and other activities of daily living.

**Increased community awareness and education about ADRD and its symptoms will help to improve safety for people with ADRD.** Community outreach can include education to community councils, media, and neighborhood groups. The Silver Alert bill mandated that the Division of Military

and Veterans Affairs and the Department of Public Safety work together to promote community-planning efforts and raise awareness among law enforcement and other first responders.

**Alaskans with dementia and their families need a first point of entry** into the dementia care system to receive diagnosis, information about the disease, and connection to appropriate community services, including counseling and peer support. Documenting the diagnosis in an individual's medical record is the first step toward comprehensive care, however connecting the primary care setting with behavioral health resources and other supportive services is also necessary. This is one of the goals of the Patient Centered Medical Home model that is currently being implemented in primary care and behavioral health settings in Alaska. To support implementation of this model, efforts are ongoing to develop and implement a successful PCMH model, although these efforts are still in early stages.

### **Fiscal Implications**

Increased cost savings and improved quality care is expected as individuals impacted by Alzheimer's and their families will be connected early with appropriate services and extend the time they are able to live independently.

Care settings adopting best practices and adhering to higher quality standards will have additional costs for staffing, training, and potential environmental modifications. This will require a tiered system for reimbursement in order for providers to make additional investments. The cost to the State for the increased rates may be offset by reductions in unnecessary hospitalizations and delayed need for higher cost services.

Modifying private homes in order to prevent falls may decrease hospital admissions and stays. This is currently the number one reason for hospital admission in Alaska.<sup>20</sup> Increased use of assistive technologies can also protect caregivers from injury and delay admission into skilled nursing facilities for people with ADRD.

## **Recommendation 3.1: Ensure safety in private homes and communities for persons with ADRD.**

### **Strategies**

1. Ensure training to local police departments, Alaska State Troopers and Village Public Safety Officers to provide appropriate emergency response services to people with ADRD.
2. Include reimbursement for home monitoring systems to maximize independence in home and community settings.
3. Use tele-health to provide specialized services, enable peer to peer counseling and ensure access to best practices in remote communities.
4. Increase use of assistive technology in the home including "Smart Home" technologies.
5. Implement a coordinated community response system such as a 'Silver Alert', 'Project Life Saver' or the use of available GPS tracking system in communities statewide.
6. Develop and implement Home Modifications for Aging in Place (HomeMAPs) statewide.

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<sup>20</sup> DHSS Public Health

## **Recommendation 3.2: Ensure safety and quality of care in residential settings.**

### Strategies

1. Increase access to expert consultation for dementia care with health care facilities in order to prevent involuntary and unnecessary evictions.
2. Develop and implement regulations for quality standards for assisted living homes and other residential settings so that caregivers' skills are appropriate to the population they serve
3. Increase capacity within the Office of Long Term Care Ombudsman (OLTCO) to conduct more frequent unannounced visits of facilities to advocate for and monitor quality of care.
4. Strengthen monitoring and oversight of licensed residential homes through increased resources to Division of Health Care Services Residential Licensing (ALHs) and Health Care Facilities Licensing and Certification.
5. Expand the volunteer ombudsman program's capacity to recruit and train local individuals to monitor quality of care within residential settings.

## **Recommendation 3.3: Strengthen the role of the primary care setting as a point of entry to the dementia care system.**

### Strategies

1. Improve service coordination particularly at points of hospital intake and discharge to ensure individuals receive appropriate care in the right setting.
2. Provide training in dementia care for primary care and behavioral health providers in Alaska.
3. Support the implementation of the Patient Centered Medical Home, which promotes a stronger linkage between behavioral health and primary care.
4. Integrate dementia care training in the Alaska Family Medicine Residency and University of Alaska Family and Psychiatric Nurse Practitioner program.
5. Reduce harmful over prescription of antipsychotic medication as a chemical restraint and intervention through increased training and outreach to primary care providers.
6. Expand the capacity to conduct medical evaluations of individuals in their home.
7. Incent and explore using Federal Qualified Health Centers to meet the needs for dementia care in their communities.

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# Goal 4: Develop a long-term services and supports workforce trained in dementia care.

## Rationale

Alaska needs a workforce that is educated about Alzheimer's disease and Related Dementia and trained in dementia care to improve quality of life and safety for persons experiencing this disease and reduce the burden of care for family and other informal caregivers. There are few dementia care requirements for providers and little incentive for providers to obtain specialized training. Untrained workers can exacerbate challenging behaviors and increase the likelihood of inappropriate placement of persons with dementia into institutional settings.

As the older adult population increases and becomes more culturally diverse, cultural competence training becomes even more important to improve care for all Alaskans affected by dementia. Health care professionals and direct service providers need assistance in order to communicate effectively across cultures and languages.

## Fiscal Implications

Increased cost for training is expected to be offset by reductions in inappropriate placements in institutional settings and improved retention and recruitment of staff. Care settings adopting best practices and adhering to higher quality standards will have additional costs for staffing, training, and potential environmental modifications. This will require a tiered system for reimbursement in order for providers to make additional investments. The cost to the State for the increased rates may be offset by reductions in unnecessary hospitalizations and delayed need for higher cost services.

## **Recommendation 4.1: Increase the level of knowledge of dementia care and caregiver competence within the long-term services and supports workforce.**

## Strategies

1. Integrate dementia care training into PCA, CNA and CMA training.
2. Develop optional dementia certifications across the long-term care workforce.
3. Establish career ladder programs in different care settings to provide additional training and compensation to staff working with patients/residents with ADRD.

4. Increase options for flexible training opportunities such as online, distance, or weekend programs.
5. Emphasize activity techniques and skills, such as music, movement and humor when working with individuals with ADRD.
6. Expand CNA and RN training in rural areas through vocational training centers, skilled nursing facilities, the University of Alaska system and school districts.
7. Develop dementia components in gerontology training at the University of Alaska.

## **Recommendation 4.2: Ensure health, human service and public safety professionals are knowledgeable about dementia.**

### Strategies

1. Increase dementia care training across the continuum of care and in complementary fields such as police, emergency services, finance, justice system, nursing, dental, optometry, social work and mental health.
2. Cross-train providers who serve people with Intellectual and Developmental Disabilities, mental health disorders or Traumatic Brain Injury to prepare for these populations aging with increased risk factors for ADRD.
3. Make dementia training available at conferences and symposia of related fields.
4. Educate health professionals and employers about ADRD and needs of caregiver using a peer to peer model.

## **Recommendation 4.3: Increase cultural competence among dementia care workers.**

### Strategies

1. Identify evidence-based national models to address cultural differences within care settings for people with ADRD and their caregivers.
2. Collaborate with ANTHC to develop a cultural competence online training module for caregivers with training hours eligible to satisfy licensing requirements for assisted living homes.
3. Develop and disseminate culturally relevant materials related to ADRD.
4. Link individuals with ADRD with services and care settings that are consistent with their cultural values and beliefs.

# Goal 5. Improve quality of life for family and other informal caregivers.

## Rationale

**Family and informal caregivers are the backbone of the long-term services and supports system for people with dementia.** Approximately 33,000 Alaskans provided 37 million hours of unpaid care to their adult family members in 2013. Family caregivers provide 80% of in-home care in Alaska and are critical to keeping loved ones living safely at home.

While family caregiving is rewarding and a personal calling for many, it is also very challenging. Family and other informal caregivers have higher levels of stress and other health problems and utilize health care at higher levels than non-dementia related caregivers. It is imperative that family and informal caregivers maintain good health, avoid social isolation, and are aware of sources of support. Regular and consistent participation in peer support groups is among the most powerful and effective means of caregiver support.

**When one person develops dementia, everyone around them is living with dementia.** In a survey of family and other informal Alaskan caregivers of the most difficult challenge faced, 18 percent said it "creates stress and makes me feel depressed." Fifteen percent responded with "it creates a financial burden" and 15 percent said it "interferes with my work." Consultation and education may reduce caregiver stress and improve quality of care. A 2010 evaluation of Washington state's family caregiver program indicates that "using consulting and education services is associated with lessening of subjective burden" for caregivers.<sup>21</sup>

Family and other informal caregivers need financial support in order to keep their loved ones living safely at home. Some states are looking at ways to provide paid Family Medical Leave Act, protect people from losing their job if they have to leave to give care and are exploring insurance options to pay for time off.

## Fiscal Implications

The cost savings to the State of enabling individuals to live safely in their home longer with a family and other informal caregiver needs to be compared to the direct costs of these strategies.

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<sup>21</sup> Chen, Hedrick, Young (2010). "A pilot evaluation of the Family Caregiver Support Program." Evaluation and Program Planning, vol.33 (2), pp. 113-119.

## **Recommendation 5.1: Maintain and improve the physical and mental health of family and other informal caregivers.**

### Strategies

1. Increase training to caregivers about ADRD, resources available and approaches and strategies for providing care and reducing stress and fatigue.
2. Increase in-home respite and adult day services to meet caregiver needs for appropriate breaks in providing care.
3. Increase one-on-one training coaching and mentoring with caregivers to resolve their issues with challenging behaviors.
4. Develop and implement a family caregiver assessment tool and incorporate it into Medicaid waiver assessments and plans of care.
5. Expand National Family Caregiver Support grant program in Alaska to include an assessment of caregiver needs
6. Increase opportunities for caregivers to learn from physical therapists or other qualified professionals on how to safely move/lift a person and how to use assistive devices such as a gait belt and lifts.
7. Increase social opportunities for persons diagnosed with ADRD and their caregivers.
8. Increase awareness of social media to lower isolation and increase skills.
9. Increase caregiver peer support groups in diverse settings such as workplaces.
10. Increase use of volunteer companions, peer support and community engagement to support people with ADRD and their caregivers.
11. Increase use of assistive technologies and in-home interventions to prevent caregiver injury such as lifts, electric plug locks, smart home sensors and monitors.
12. Increase funding for counseling by licensed clinical social workers and other qualified professionals for family caregivers to resolve preexisting personal problems that complicate caregiving.

## **Recommendation 5.2: Develop a coalition of families and agency representatives to advocate for policy changes to support family and other informal caregivers and to decrease the financial burden of caregiving.**

### Strategies

1. Explore incentives to decrease the financial burden on caregivers providing care such as tax incentives, health insurance coverage, deferred income incentives, and non-monetary support through access to financial planning and counseling.
2. Increase workplace protections for employed family caregivers including employment nondiscrimination laws, and accrual of paid leave for the purpose of caregiving tasks.
3. Educate employers on benefits of flexible work schedules.



# Goal 6. Increase monitoring and research into ADRD prevalence, cost of care, prevention and treatment.

## Rationale

The incidence of ADRD is rapidly increasing in Alaska and is becoming a public health crisis. Collecting data to understand the prevalence and impact of ADRD will allow for the best stewardship of public funds by identifying the priority needs of those affected by ADRD. Currently there are no unduplicated counts of individuals with ADRD utilizing state programs. This makes it difficult to understand the true cost of care strategies.

While large research trials are more difficult in Alaska with its small population, there are still opportunities for research on the possible ways to prevent or delay onset of the diseases and on best practices to treat those with ADRD. Research will also lead to improved health outcomes for everyone affected by ADRD.

## Fiscal Implications

Fiscal implications of conducting research in Alaska will need to be assessed.

## **Recommendation 6.1: Maintain and expand research to understand ADRD prevalence, utilization and cost of care in Alaska.**

## Strategies

1. Use existing DHSS data to identify the unduplicated number of people with ADRD served by DHSS programs each year and quantify the cost per person served. Use this to project future baseline costs and fiscal implications of changes in service lines and policies.
2. Access CMS, private insurance and out of pocket costs to analyze cost of in-patient and out-patient services for Medicare beneficiaries for persons receiving Medicaid services across the continuum so that there is a complete picture of the total individual and collective health care costs for Alaskans.
3. Maintain funding to use the Behavioral Risk Factor Surveillance System (BRFSS) to collect health outcomes data for persons with Alzheimer's disease and related dementia. Use BRFSS to gather caregiver information.
4. Work with ANTHC to identify number of people served with ADRD.

## **Recommendation 6.2: Maintain and expand research of ADRD best practices related to risk reduction, treatment and care.**

### Strategies

1. Research and evaluate impact of Patient Centered Medical Home model on ADRD.
2. Collaborate with tribal partners, National Resource Center on American Indians, Alaska Natives, and Hawaiian Alaska Native Elders Resource Center at the University of Alaska Anchorage and ANTHC to better understand impact of ADRD among Alaska Native Elders and communities.
3. Support University of Alaska research related to ADRD.
4. Seek partnerships with major research institutions in the polar north or Pacific Northwest to understand best practices for ADRD in northern latitudes.
5. Support development of capacity for clinical trials of ADRD medication, pilot projects of effective care models and research into symptom management in Alaska using specific research where possible.
6. Seek federal grant opportunities to support research.

# 5. Implementation Plan

The core team will meet quarterly to guide the implementation of the Roadmap and track progress. Each member of the core team is convening a workgroup to implement the first seven priority strategies over the next few years. The core team conducted a survey of stakeholders to help determine the priority strategies. One of the questions asked stakeholders if they wanted to be part of implementing the strategy. The core team will also invite these stakeholders and others to be a part of the workgroups.

The implementation table outlines the strategy and the convening organization. The assembled workgroup will identify co-chairs of the workgroup, as well as action items, tasks, a timeline and performance measures to track progress. After the implementation table is a list of all potential stakeholders to help implement the Roadmap. This list can be referenced as new strategies are selected. The list of stakeholders interested in specific strategies is available through the Trust.

## Implementation Table

Strategy	Convener
<b>1.1.1</b> Educate Alaskans about prevention, diagnosis, treatment, costs and appropriate care for people with ADRD through all possible media, in-person presentations, and policy advocacy.	Alzheimer's Resource of Alaska
<b>2.1.1</b> Assess feasibility and design an implementation plan for a potential 1915 (i) and 1915 (k) HCBS State Medicaid Plan amendments.	The Trust
<b>2.4.1</b> Identify the DHSS resources needed through 2025 and 2035 to ensure those with ADRD can remain living safely in their own home or family caregiver's home for as long as possible.	Senior and Disabilities Services
<b>3.2.1</b> Develop and implement regulations for quality standards for assisted living homes and other residential settings so that caregivers' skills are appropriate to the population they serve.	Office of the Long Term Care Ombudsman
<b>4.2.1</b> Increase dementia care training across the continuum of care and in complementary fields such as police, emergency services, finance, justice system, nursing, dental, optometry, social work and mental health.	Pioneer Home
<b>5.1.1</b> Increase training to caregivers about ADRD, resources available and approaches and strategies for providing care and reducing stress and fatigue.	AARP
<b>5.1.2</b> Increase in-home respite and adult day services to meet caregiver needs for appropriate breaks in providing care.	Alaska Commission on Aging

## Stakeholders + Potential Resources

- AARP
- Access Alaska
- Advocacy organizations and partner boards
- AgeNet
- Aging and Disability Resource Centers
- Alaska Academy of Family Physicians
- Alaska Bar Association
- Alaska Behavioral Health Association
- Alaska Board of Nursing
- Alaska Brain Injury Network
- Alaska Center for the Blind
- Alaska Commission on Aging
- Alaska Court System
- Alaska Department of Administration
- Alaska Department of Health and Social Services
  - Behavioral Health
  - Division of Public Health,
  - Health Care Services
  - Office of Rate Review
  - Residential Licensing
  - Senior and Disabilities Services
- Alaska Department of Labor and Workforce Development
- Alaska Department of Military & Veterans Affairs
- Alaska Department of Public Safety
- Alaska Department of Transportation
- Alaska E-Health Network
- Alaska Family Medicine Residency
- Alaska Housing Finance Corporation
- Alaska Legal Services
- Alaska Medical Association
- Alaska Mental Health Advisory Board
- Alaska Mental Health Trust Authority
- Alaska Mobility Coalition
- Alaska Municipal League
- Alaska Native Regional Health Corporations
- Alaska Native Tribal Health Consortium
- Alaska Nurse Practitioners Association
- Alaska Office of Long Term Care Ombudsman
- Alaska Primary Care Association
- Alaska State Hospital and Nursing Home Association
- Alaska State Legislature
- Alaska State Troopers
- Alaska Transit Coalition
- Alaska Vocational Technical Center
- Alzheimer's Resource of Alaska
- Assisted Living Provider Association
- Board of Nursing
- Bridge Builders
- Center for Visually Impaired
- Centers for Medicaid and Medicare
- Community Care Coalition
- Cultural organizations active in local communities
- Discharge Planners and Hospitals
- Elder Bar Attorneys
- Governor's Council on Disabilities and Special Education
- Health Workforce Coalition
- Hospice organizations
- Local Fire Department and Police
- Mat-Su Health Foundation
- Physical therapists
- Project Lifesaver representative
- Providence Alaska
- Provider Associations + organizations
- Regional Housing Authorities
- Rural colleges
- Statewide Independent Living Councils and Centers
- Tanana Chiefs Conference
- UAA Trust Training Cooperative
- University of Alaska
  - Institute of Social and Economic Research,
  - Anthropology Department
  - National Resource Center
- Veterans Administration System

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