

A Call for Action:

Alaska's 10-Year Map to Address Alzheimer's Disease and Related Dementia

January 2021





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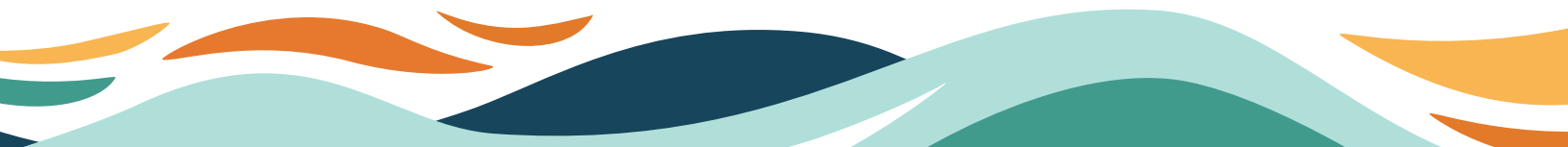
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Prologue

Rivers are life sustaining. They connect people, serve as the information highway between villages, support the livelihood of families and communities, provide connections to mother earth, play an integral role in cultural traditions, stories, and values, and help families and friends stay connected. Rivers are dispersed, consisting of tributaries and smaller creeks that flow out to the ocean. The look, feel, and temper of the river is influenced by the changing seasons. The river is a metaphor for identity, wellbeing, and connection to ourselves, family, community, and environment.

As we age, our journey down the river is filled with stops: to visit family, to start our own family, to engage in subsistence or other work activities, and to settle down and enjoy the fruits of our labor as we age. Each bend in the river brings with it new memories, and over time the river changes direction, slows down, and adapts to its environment.

The changes in rivers are similar to the changes in our brains due to Alzheimer's Disease and Related Disorders, or dementia. Dementia changes our brains, our relationships, our sense of self, and our ability to feel safe. It requires us to adapt. While the river of memory may change due to environment, changing seasons, or other forces, the memories still remain, especially the long-term memories created as a child. Just as the river changes with the seasons, we each go through different seasons in our lives. If we become disconnected from the river (our memories) we still have our identity and sense of self and place. Rivers carry many things; similarly, memory loss is not the only facet to dementia. The dementia diagnosis carries many things as well – various health conditions, personality changes, and increasing need for assistance.



Just as breakup and log jammed ice or other tangled debris in the river can cause the water to rise, plaques and tangles in our brains cause jams. River flooding may lead to a natural disaster, something uncontrollable or unstoppable and even seen as a threat to the survival of our families and communities. Nature can be unpredictable or shrouded in fog, making it difficult to predict or plan for, just like dementia is difficult to predict or plan for and can disrupt family and community life. While the river looks calm on the surface, just below unpredictable events have changed our lives, our memories, and our neural connections. Unforeseen disruptions result in changing water patterns or flooding which are not always noticeable until years later, just like the hidden, unpredictable, and permanent changes to our brain as a result of dementia.

Just as each neural pathway will always contain short and long-term memories even if we can't access them, the rivers also contain our memories that will continue to flow and join the larger collection of memories in the ocean. No matter what happens, the memories we carry are grounded in the river. Sitting on the riverbank, smelling the tundra, hearing the gurgling water, brings us back to other times, just like sitting with family and friends reminds us we are all connected.

- Written by Dr. Jordan Lewis



Executive Summary

Alaska is one of the fastest aging states in the nation. An aging population means an increase in a difficult diagnosis: Alzheimer's Disease. Every person with Alzheimer's Disease eventually requires round-the-clock care. Alaska is not prepared to meet this quietly encroaching epidemic.

This plan is an urgent call to action. The needs of Alaskans with Alzheimer's Disease and Related Dementia (ADRD) are complex and require an ongoing focused action-oriented commitment to address the many layers, funding mechanisms, and solutions needed to build a sustainable system capable of addressing this public health challenge.

This document provides context and describes the current systems of support. It highlights Alaska's promising practices as well as outlines the many gaps and needs. These needs defined six overarching goals which frame the next decade of work.

These goals are:

- 1. Expand services**
- 2. Build a workforce**
- 3. Support informal/family caregivers**
- 4. Promote early diagnosis and healthy behaviors**
- 5. Monitor prevalence and outcomes**
- 6. Support innovation and research**

This plan does not define what we must do. You will not find timelines with measurable outcomes, specific strategies, or details regarding the financial investment needed to build the necessary infrastructure.

Instead, it maps out the journey and points to the next step: to create the Next Generation Dementia Action Collaborative. This group of stakeholders will commit to meeting on an ongoing basis, guided by a detailed strategic plan to be developed on an annual basis which includes specific strategies, resources and outcomes based on the current priorities. The Collaborative will work with funders to ensure the work moves forward to build the system to meet the needs of today as well as the needs of tomorrow.

Background

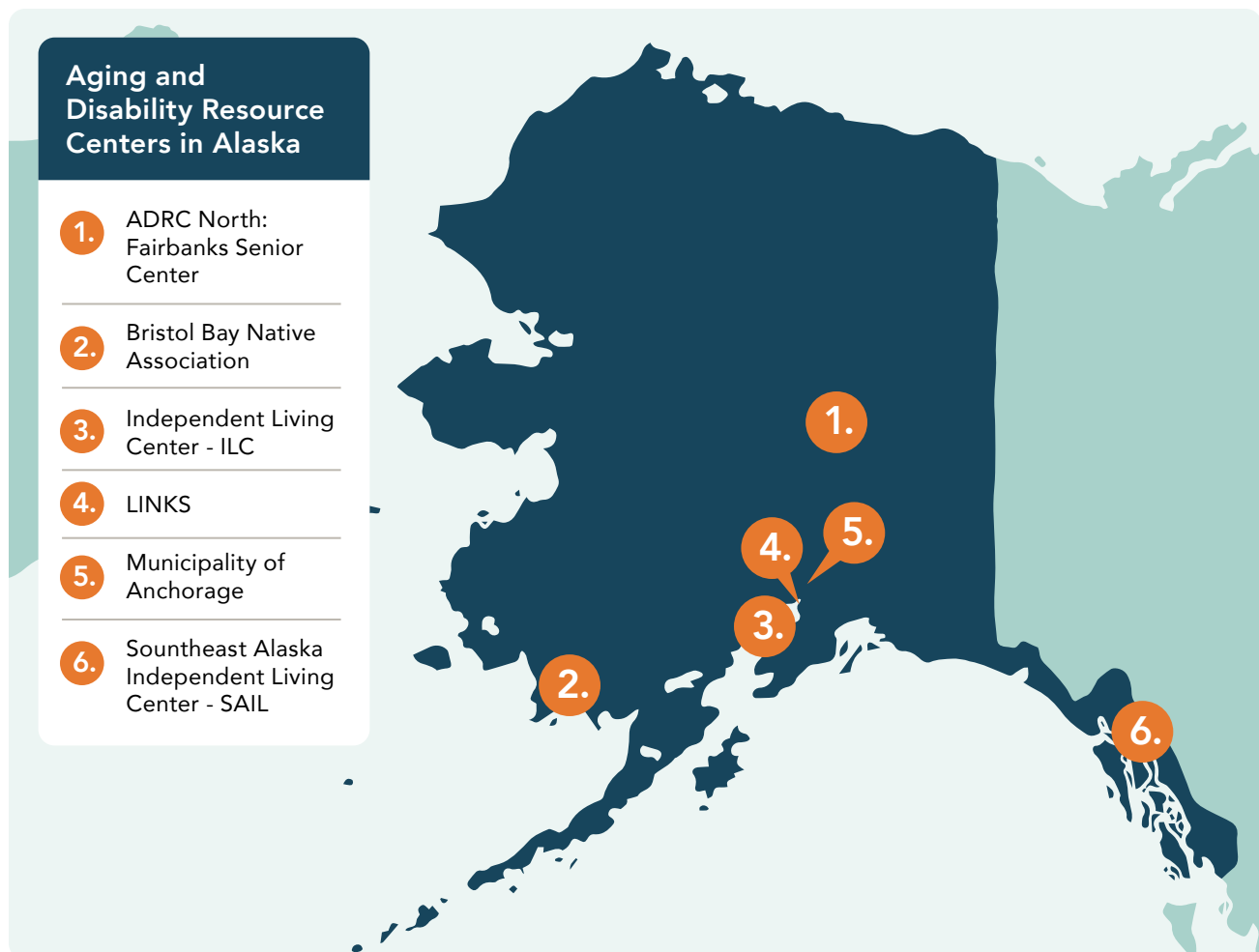
Inspired by the rapidly increasing number of Alaskans with ADRD, Alaska's Roadmap was initiated in 2014 by the Alaska Commission on Aging.

The 2014 plan defined the problem of increasing numbers outpacing available resources; recommended increased efforts specific to public awareness; guided decision-making on allocation of current resources; and increased Alaska's focus on family caregivers.

While there were several projects inspired by the 2014 plan, progress on the recommendations and activities in subsequent years was not consistently tracked. The Alaska Mental Health Trust Authority funded this work in 2020 to provide a longer-term guide and process to advance plan recommendations.

The plan developed in 2020 builds on this important 2014 work. Additionally, the Core Planning Team focused on implementation, planning for emerging opportunities and technologies, and including Alaska's rural and Native cultural perspectives.

Great distances in Alaska - as seen in the map below - contribute to this public health challenge.



What is Alzheimer's Disease and Related Dementia (ADRD)?

Dementia describes a group of symptoms associated with a decline in memory, reasoning or other thinking skills. Many different types of dementia exist, and many conditions cause it.

Dementias are often grouped by what they have in common, such as the protein or proteins deposited in the brain or the part of the brain that is affected. Some diseases look like dementias, such as those caused by a reaction to medications or vitamin deficiencies, and they might improve with treatment. Progressive dementias that are not reversible are grouped together, with Alzheimer's being the most common. ([Mayo Clinic, 2019](#)). This plan focuses on this group of dementias which include the following types (in addition to Alzheimer's Disease):

- Vascular
- Lewy body
- Frontotemporal
- Mixed

Alzheimer's Disease is the most common cause of dementia and accounts for an estimated 60-80 percent of cases. Though the greatest known risk factor for Alzheimer's is increasing age, the disease is not a normal part of aging. And though most people with Alzheimer's are 65 and older, approximately 200,000 Americans under 65 have younger-onset Alzheimer's Disease. As Alzheimer's advances, symptoms get more severe and include disorientation, confusion and behavior changes. Eventually, speaking, swallowing and walking become difficult. There is currently no way to cure Alzheimer's disease. (Alzheimer's Association, n.d.)

How the ADRD Map was developed

This plan was developed in three stages: research, team discussion and stakeholder input. A consultant team worked with a Core Planning Team comprised of twenty-one representatives that included family caregivers, policy makers, funders, service providers and advocates.

The Core Planning Team met monthly for six months to review information, discuss presentations made by subject matter experts, and identify critical needs as well as strengths and successes.

METHODOLOGY

The plan development process generally followed this timeline:

JUNE	Project kick-off meeting with the planning team.
JULY	Review past Roadmap. Discuss stakeholder engagement process and schedule.
AUGUST	Present results of environmental scan including promising practices to consider (i.e. technology).
SEPTEMBER	Rural Alaska – unique needs, challenges and opportunities; presentations by Agnes Sweetsir and Dr. Bruce Finke.
OCTOBER	Draft plan presented to planning team in preparation for larger event.
NOVEMBER	Webinar for public comment on proposed plan components; also discussed Next Gen workgroup with core planning team.
DECEMBER	Finalize Plan.

RESEARCH

The consultants conducted an environmental scan of national and state plans and presented this research to the Core Planning Team. The team provided information on Alaska's systems and programs. The Core Planning Team then identified priorities and issues to direct this work.

PLAN REVIEW

The draft plan was presented at a public webinar with 88 registered participants. Participants provided feedback during the webinar as well as via a web-based survey distributed after the webinar. The webinar was recorded and available for viewing following production. Thirty-two people responded to the survey.

The Core Planning Team reviewed two drafts of the plan prior to the webinar, and a review draft of content in early December 2020. Following their review and comments, the consultants finalized the plan in January 2021.

Purpose of Alaska's ADRD Map

This plan has three purposes, but one stands above the other two: to inspire action. This plan's primary purpose is to fuel a collective effort toward improving Alaska's systems of supporting people with ADRD and their families.

The other two purposes are:

- To identify the strengths and needs of Alaska's systems and the Alaskans they assist; and
- To define a process for meeting the goals of the plan.

How to use the ADRD Map

This plan is written with many different readers in mind. Our hope is to provide enough information for the reader to be informed about the realities and opportunities related to ADRD in Alaska while offering references to more in-depth information for people who are interested. It is not meant to be a comprehensive review of every service or project.

The main body tells the current story of ADRD in Alaska; the appendices contain data, resources, and references for those who wish to seek out more information.

Throughout the document we include first-hand stories from a variety of perspectives on ADRD. The plan is structured so that the stories lead the reader through the experiences of ADRD, from caregivers' perspectives to policy and program perspectives.



Who this is for: The audience

This plan has several audiences. We hope that it will be used by

- Policymakers at all levels;
- Community leaders (tribes, municipalities, boroughs, villages);
- Funders—not just the State of Alaska, but insurers, philanthropists, and other payors;
- Current service providers: for profit and nonprofit home and community service providers, physicians, nurses, senior centers, aging and disability resource centers, senior housing providers, assisted living providers, nursing home leadership, and others;
- People with dementia and their families, friends and advocates; and
- The next generation of families & providers: the generation that will be caring for their parents, aunts, uncles, and others in their family and community.



Overview

The Vision: What we want to achieve by 2030

Alaska succeeds in meeting the needs of residents impacted by Alzheimer's Disease and Related Dementia through community-driven initiatives supported by a highly coordinated collective statewide effort that embraces cultural strengths and encourages innovation.

The Mission of this Plan

To coordinate the work of building a robust system of support for people impacted by ADRD.

Principles

These principles were set out in the 2014 Plan, and continue with the revised ADRD Map:

- Prioritize early detection and planning:
 - o Early detection and planning can vastly improve quality of life and ease the financial burden for individuals with ADRD and their caregivers;
- Support staying in or close to home:
 - o Individuals with ADRD should be able to reside in their homes and communities for as long as possible; and
- Address costs through investing in early intervention and services in least restrictive setting.
 - o As the prevalence 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.

In this revision, we add this principle:

- Understand and integrate cultural perspectives of people with dementia and their families.
 - o Culture has a big influence on understanding of early detection, the way family and communities respond, and how needs are addressed during a person's life.

Goals

Alaska is committed to achieving the following goals by 2030:

Goal #1

Expand service options and capacity of the systems of care to meet the increased number of Alaskans with ADRD

The number of Alaskans with ADRD will double in the next ten years. The service options, and funding for those options, has not kept up with the demand. In order to manage costs by supporting care in the least restrictive environment, Alaska needs to increase the service options, both in and outside of the home. In addition to expanding current service capacity, Alaska should consider flexible service models similar to the Veteran Directed Care program.

Goal #2


Establish a dementia-capable workforce ready to meet the needs of all Alaskans with ADRD

There is an insufficient number of direct support professionals (DSPs) to provide the care today. The number of DSPs needed is only going to increase. Many DSPs do not have specific dementia training. Much progress has been made in this area since the 2014 Roadmap with implementation of the Positive Approach to Care™ model and the CNA Dementia Care Apprenticeship Program. But Alaska is facing a rapidly aging population and a decreasing number of working age adults. An additional need is a workforce with specialized skills and increased compensation to support individuals with ADRD who have challenging behaviors.

Goal #3

Create resources and information that are readily available and make family caregivers feel supported and capable

Caring for family caregivers is not “nice to have”. It is an integral part of the ADRD service delivery system. There are many reasons to support family caregivers beyond the cost-effectiveness of at-home care. The longer people with ADRD are able to stay home, the better it is for their health. We also know that caregivers are at increased risk for many health issues. It’s important that Alaska realizes the different resources needed and available across regions and communities. Information and support need to reflect these differences.



**Goal
#4****Establish the importance of prevention and early diagnosis in communities statewide and throughout Alaska's healthcare system**

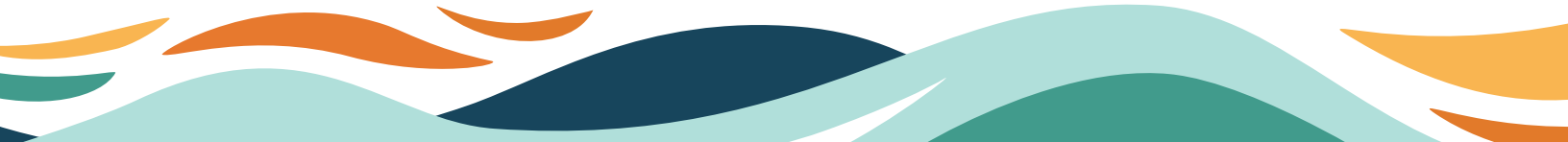
While there is no cure for Alzheimer's Disease and other dementias, much has been learned about slowing the onset and progress of the disease. Healthy aging and brain health practices share many of the same approaches as other public health measures. Yet because of stigma around ADRD, many are reluctant to talk about concerns regarding memory or brain health with their medical providers. As with prevention, there is much to be gained from early diagnosis. Individuals and family members can get connected with resources earlier, put systems in place for safety, and have important discussions about the person's wishes. Financial planning is an important part of preparing for later stages.

**Goal
#5****Develop a system that consistently monitors the prevalence of ADRD and the impact of ADRD-related initiatives**

No entity in Alaska is specifically focused on ADRD, aside from Alzheimer's Resource of Alaska, a nonprofit provider organization. Healthcare providers, services and funders are fragmented. There is no way currently to count the number of people who are diagnosed with ADRD – prevalence is based on demographic information. In addition, because of the fragmentation, there is not a clear understanding of what's working or not working across the state. Consistent, clear data is necessary to inform priorities and project development.

**Goal
#6****Promote innovation and research into effective interventions**

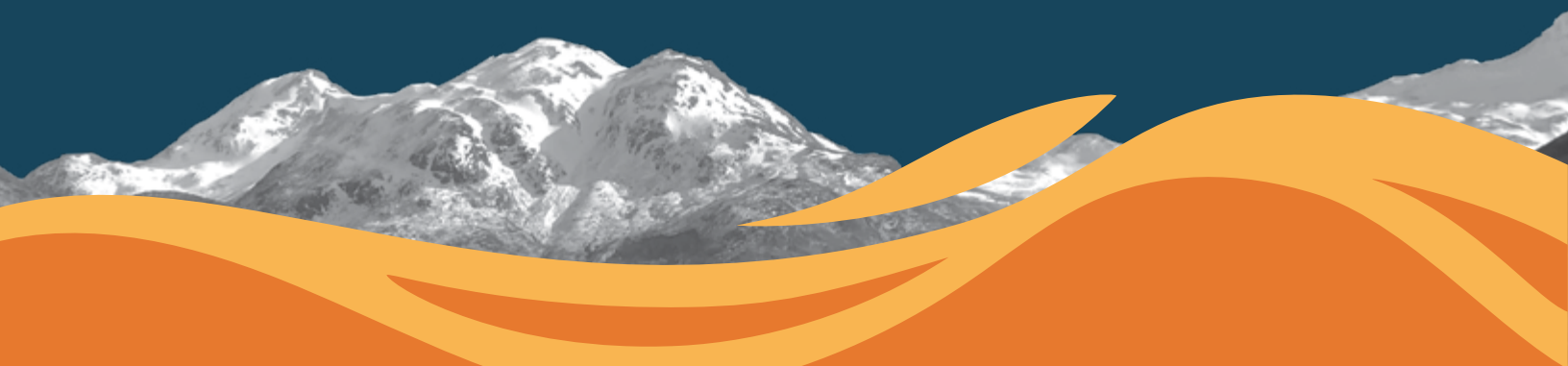
Alaskans deserve to have access to cutting-edge medical interventions and treatment options. This includes emerging assistive and smart home technologies, as well as psychosocial interventions that have evidence-based results. Hundreds of millions of dollars are currently being invested in ADRD research. The National Alzheimer's Association alone is spending \$208 million in 31 countries. Alaska must stay connected to efforts around the globe addressing ADRD.



ADRD in Alaska: The People

The number of people with ADRD in Alaska is growing quickly. Alaska is one of five states with the highest projected increase in percentage of people with ADRD. The other states are Nevada, Arizona, Wyoming and Vermont.

- ADRDs are estimated to affect 12,500 Alaskans over the age of 65.
- By 2030 the number of elders with ADRD will almost double, to 23,900 older adults. (State of Alaska, Alaska Commission on Aging, 2019)
- In 2019, Alzheimer's Disease was the sixth leading cause of death in Alaska, claiming 131 Alaskans that year. (State of Alaska Division of Public Health, Health Analytics and Vital Records, 2020)



Dementia is the leading contributor to disability and dependence among older adults. In 2019, Alzheimer's and other dementias will cost the nation \$290 billion, including \$195 billion in Medicare and Medicaid payments. By 2050, Alzheimer's is projected to cost more than \$1.1 trillion. This dramatic rise includes more than four-fold increases both in government spending and in out-of-pocket spending. (Alzheimer's Association, 2019)

Data and diagnosis

Data is based on prevalence where it is collected, and prevalence data is limited, largely because of inconsistent data collection across states and communities. In Alaska, the only information collected consistently at a statewide level is through the Alaska Behavioral Risk Factor Surveillance System (BRFSS), managed by the Division of Public Health. The BRFSS is a telephone survey that asks adults about their health, as well as behaviors that could affect their health. The inclusion of the caregiving module in the BRFSS is an outcome of the 2014 Roadmap, which identified data collection as a critical need. While this is progress, the BRFSS survey is a random telephone survey of all Alaskan adults. Data collected through the BRFSS becomes available a year later. Thus, information from this source is not current and is based on a limited sample. Statistics on ADRD in Alaska are based primarily on national data about the percentage of people diagnosed with ADRD as they age. That percentage is then applied to Alaska's demographic information.

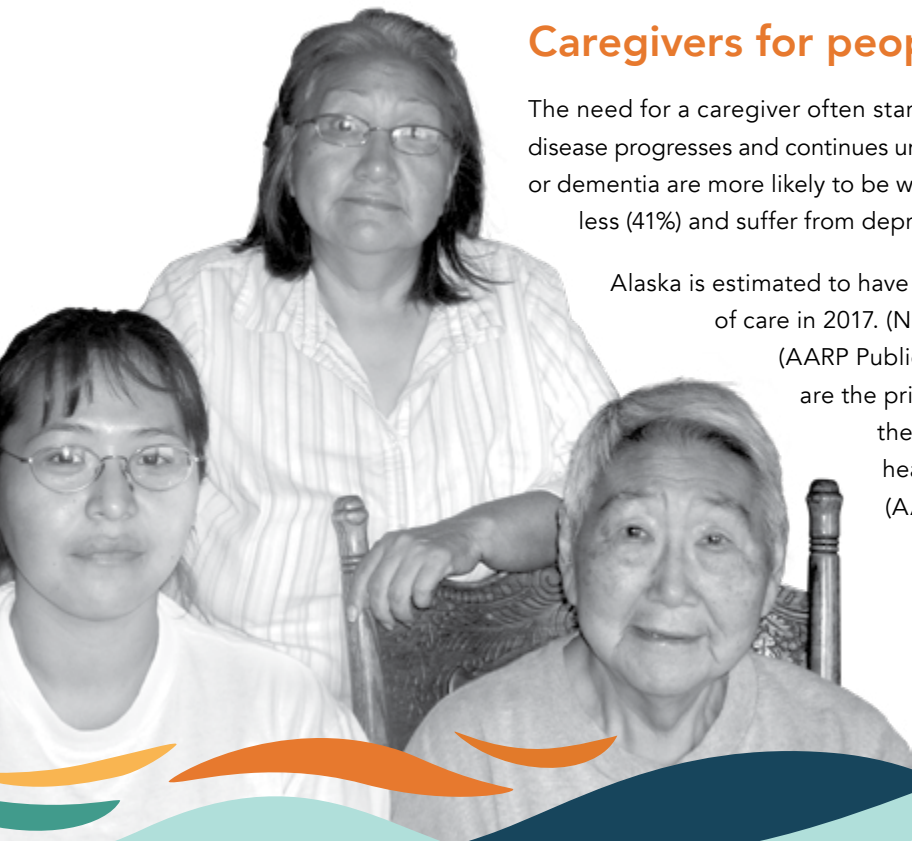
Native people and dementia

Only a few studies have examined Alzheimer's and other dementias in the American Indian community. In one study, researchers used 14 years of data from a large Northern California health plan to examine dementia incidence, people who received a new diagnosis of dementia per year, among different racial and ethnic groups. The study found that American Indian members of the health plan had a somewhat higher incidence rate of diagnosed dementia than white plan-members (22.2/1,000 person-years vs. 19.3/1,000 person-years). Based on 14 years of these data, researchers estimate that one in three American Indian and Alaska Native older adults (65 and older) will receive a dementia diagnosis over the next 25 years. (Mayeda, Glymour, Quesenberry, & Whitmer, 2016)

Caregivers for people with dementia

The need for a caregiver often starts early in the disease process, intensifies as the disease progresses and continues until death. Caregivers of individuals with Alzheimer's or dementia are more likely to be women (66%), have household incomes of \$50K or less (41%) and suffer from depression (30-40%).

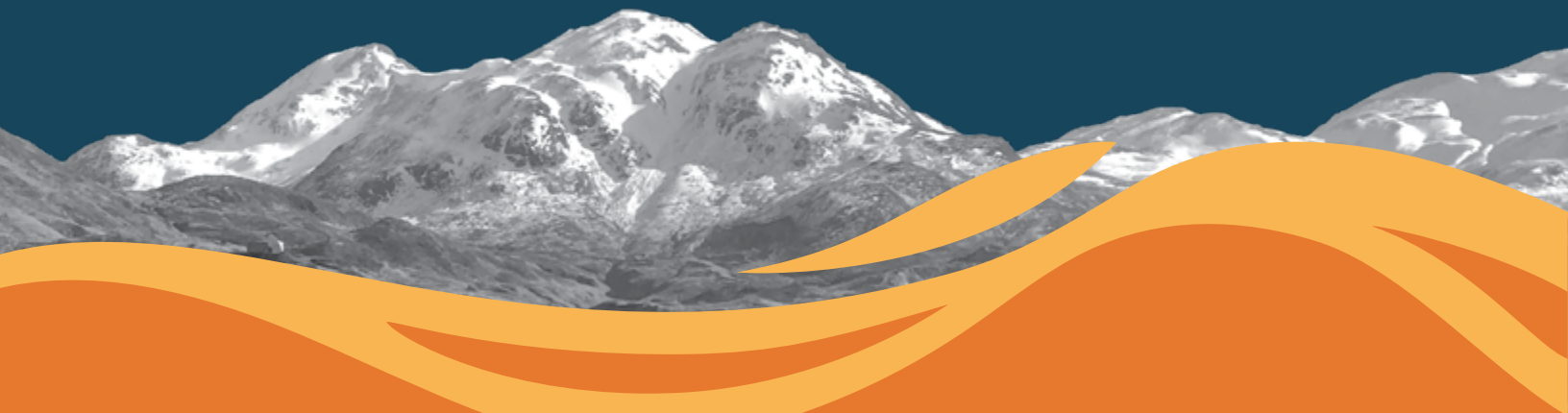
Alaska is estimated to have 82,000 caregivers providing 69 million hours of care in 2017. (Note: This is for all caregiving, not just for ADRD) (AARP Public Policy Institute, 2019) While family caregivers are the primary source of support to people with dementia, they are not widely recognized for their value by health care and long-term care service providers. (AARP Public Policy Institute, 2019)



Current State of the State

Alaska's health-related services are comprised of two government systems – state government, which is a conduit for federal funds such as Medicaid, as well as grant funds – and tribal governments, which are the link to American Indian/Alaskan Native federal funding sources like the Indian Health Service and Title VI. Collaboration between Title III and Title VI providers is encouraged in order to make more services available for older Alaskans.

Supports and services for people with ADRD are typically provided along a continuum of care, from services provided in homes and communities to more intensive services provided in assisted living and, at the highest level of care, in skilled nursing facilities and acute medical hospitals (see graphic). (State of Alaska, Alaska Commission on Aging, 2019)



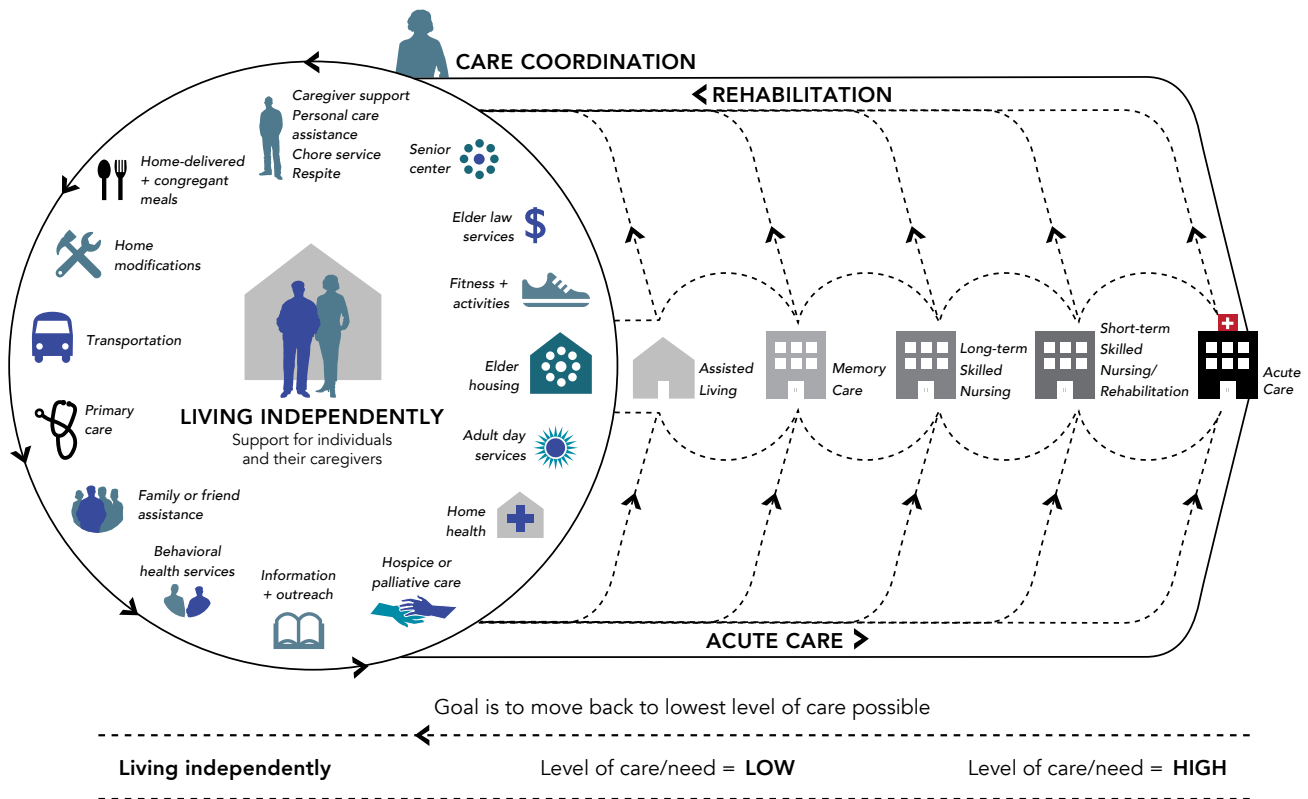


Figure 1 Long-term Services and Supports Continuum of Care for Seniors. Graphic Credit: Agnew::Beck Consulting 2019

State of Alaska

STATE MANAGED PROGRAMS

The Alaska Department of Health & Social Services Division of Senior and Disabilities Services funds grants and Medicaid for home and community-based services to low-income people with certain healthcare needs related to aging and disability, including ADRD.

Alaska has no Area Agencies on Aging, as some other states do. The Alaska Commission on Aging takes the lead on planning activities, advocates for increased resources for senior programs, and promotes public awareness about senior matters.

MEDICAID PROGRAMS

Medicaid is the primary payor for assisted living through waivers, and for nursing home care through the Medicaid State Plan. The waivers are based on functional, cognitive, and behavioral needs. Many people with dementia do not meet the cognitive standard because they are early in their disease. Alaska does not have a Medicaid waiver that pays for services needed specifically because of dementia. In FY19 and FY20, over one-third of individuals on the Alaskans Living Independently waiver had a diagnosis of dementia (788 in FY19 and 772 in FY20).

The Medicaid program serving the most people statewide is the Personal Care Services program. The program served 2,538 people in FY20. About 10% of the Alaskans using this program have a diagnosis of dementia (181 in FY20). The Community First Choice program (new in 2018) provides for much the same type of care as the Personal Care Services program. Almost 18% of people in this program had a diagnosis of ADRD in FY19, and almost 20 percent had a diagnosis in FY20.

Between the Personal Care Services and Community First Choice programs, 3,244 people were served in FY20 (Correspondence, Anthony Newman, Senior & Disabilities Services, 12.13.20)

GRANT PROGRAMS: STATE AND FEDERAL TITLE III

The Department of Health & Social Services is the State of Alaska's designated state unit on aging. The Division of Senior & Disabilities Services issues grants to community organizations that make services possible. (State of Alaska, Alaska Commission on Aging, 2019).

Thirty-three senior centers rely on federal and state grant funding through the State of Alaska, as do six Aging and Disability Resource Centers. The state funds grant services that include Respite, Chore, Adult Day, Case Management, Education, and Family Caregiver Support. Almost half of adult day services and family caregiver support services (44.6% and 46.2%) assist people with ADRD. State spending on senior services has been flat for at least five years while the number of people needing services has increased, resulting in a reduction in funding per person.

The Alaska State Plan for Senior Services FFY2020-2023 has a comprehensive description of the services available to all seniors as well as detailed information on demographic trends. (State of Alaska, Alaska Commission on Aging, 2019)



To Everyone On The Planet

My family is so blessed to be able to take my mom to this affordable adult (day) center so that we can have a respite from the stress of taking care of my 80-year-old mother that is in mid-stage dementia. They all have so much patience with my mother that on some days I just cannot find within myself. Knowing that mom likes going to "HER CLUB" takes away any guilt that I may have for taking time for myself ... I feel that we are a team and I need my teammates now more than ever ...

Tribal Elder Care

All of Alaska's tribal health organizations are self-governing under PL94-638 and provide services through negotiated agreements with the [Indian Health Service](#) (IHS), as well as by reimbursement from Medicaid and third-party payers.

INDIAN HEALTH SERVICE: AUTHORIZED BUT NO APPROPRIATION FOR ELDER CARE

The Indian Health Service (IHS), an agency within the U.S. Department of Health and Human Services, is responsible for providing federal health services to Alaska Natives and American Indians. The provision of health services to members of federally recognized tribes grew out of the special government-to-government relationship between the federal government and Indian tribes. Alaska has 228 federally recognized tribes.

The Indian Health Care Improvement Reauthorization and Extension Act of 2009 gave the IHS ground-breaking authority for provision of long-term care. This act amended the Indian Health Care Improvement Act and was included in the Affordable Care Act. However, Congress has not appropriated funds for long-term services and supports.

ALASKA NATIVE HEALTH CARE SYSTEM

The [Alaska Area Indian Health Service](#) works in partnership with Alaska Native Tribes and Tribal Organizations to provide comprehensive health services to Alaska Natives across Alaska, including long-term care services and supports for elders and younger individuals with disabilities. The [Alaska Tribal Health Compact](#) with the IHS is a comprehensive system of health care that serves all 228 federally recognized tribes in Alaska. IHS-funded, tribally managed hospitals are located in Anchorage, Barrow, Bethel, Dillingham, Kotzebue, Nome and Sitka.

FEDERAL TITLE VI GRANT PROGRAMS

Currently, Tribes operate 44 federally funded [Title VI Programs](#) across Alaska. Title VI programs provide home and community-based services for Alaska Native, American Indian, and Native Hawaiian elders as well as caregiver support services.

Title VI provides funding to Tribal organizations to offer a range of services to older American Indian/Alaska Native adults, similar to services provided through Title III funding, including:

- Congregate and home-delivered meals
- Information and referral
- Transportation
- Personal care
- Chores
- Health promotion and disease prevention, and
- Other supportive services.



Native Village of Unalakleet

The Elders' Nutrition Program provides congregate lunch and transportation for Elders from September through May each year. Elders over 60 years of age and older can participate in the lunch program at the Community Hall, and for those Elders who are homebound, lunch can be delivered to them. The Elders' lunch program provides opportunities for gathering, socializing with friends, and sharing a laugh over home cooked style meals.

ADRD-specific services

Alzheimer's Resource of Alaska is currently the only organization in the state specifically focused on addressing the needs of Alaskans with ADRD. While one in three people will be diagnosed with ADRD by the age of 85, publicly funded resources and services must meet the needs of all older Alaskans. Attempts to address the unique needs of people with ADRD – both at an individual level as well as at a system level – are fragmented because they are generally merged with the needs of all aging Alaskans. Because the percentage of older adults is increasing quickly,

the number of people with ADRD is as well. The systems of care described previously are not necessarily designed or prepared for people with ADRD.

For example, assisted living is defined as a setting where the residents are aided with activities of daily living. ADRD management and support is not specifically identified as a need addressed by assisted living. While most assisted living homes serve people with an ADRD diagnosis, eligibility for funding for these services is based primarily on the physical needs for assistance, not needs related to cognitive decline. A person may have advanced ADRD and require round-the-clock care but be physically capable and therefore not qualify for publicly funded services like respite.

While there are assisted living facilities that self-identify as memory care facilities or have dedicated dementia care neighborhoods, Alaska has no formal standards defining the expectations of this care. Specialized care could range from having a room/facility with the ability to restrict movement, such as locked units, to providing staff with specialized training and experience.

ALASKA PIONEER HOME CAPACITY BUILDING

The Alaska Pioneer Home and Alaska Veterans Home system is established in Alaska Statute. The homes are maintained and operated under the State of Alaska, Department of Health and Social Services, Division of Alaska Pioneer Homes. The six Alaska Pioneer Homes are located in Ketchikan, Sitka, Juneau, Anchorage, Palmer and Fairbanks. The Pioneer Homes are licensed as assisted living facilities, although they are able to provide many nursing services.

The Pioneer Homes are recognized for the highly specialized care they offer individuals with Alzheimer's disease and related cognitive dementias. This delivery of compassionate care to such a vulnerable population requires increased



staffing ratios, mandatory staff training requirements, and specialized equipment offered in the dementia neighborhoods. ((State of Alaska, Alaska Commission on Aging, 2019)

The Alaska Pioneer Home system has made the following changes in the last few years in response to the increasing needs of residents with ADRD:

- Increased staff training related to dementia through a CNA Apprenticeship program in Dementia Care as well as using the Positive Approach to Care™ training materials for all staff.
- The Anchorage Pioneer Home is remodeling its fourth floor specifically for elders with high care needs due to dementia. The goal is to have staffing levels and additional training to be able to care for people who may have struggled in other living situations. This includes elders who have behaviors that are exceedingly difficult to understand or resolve. In addition, elders who have a history of problems before they are given a diagnosis of dementia might do well living in this setting.
- In 2020 the Alaska State Legislature approved lowering the eligibility age from 65 to 60 in order to accommodate Alaskans experiencing early-onset ADRD in need of care.



Alaska's Successful Practices

Alaska has a number of successful and innovative programs that are positively impacting the lives of people affected by ADRD. Below are just a few examples; we recommend building on these successes.



Integrating Culture into Care

Culture has a tremendous role in a person's sense of well-being. Alaska is a multicultural state. Alaska Native people are the second largest ethnic group (15.6%), followed by Hispanic (7.3%) and Asian (6.5%) in July 2019. (U.S. Census Bureau, 2019) Alaska's rural nursing homes and assisted living homes are known for incorporating culture into care, from Cordova to Nome, Kotzebue, Bethel and places between. While the examples below are Alaska Native cultures being integrated into long-term care facilities, people from many cultures in Alaska receive support in culturally specific ways.

DENALI CENTER

The Denali Center is a 90-bed nursing home located in Fairbanks, Alaska. It is part of Fairbanks Memorial Hospital and owned by Foundation Health.

- The Denali Center embraces the importance of culture. Alaska Native people have a strong connection to their cultural practices and traditions. The Center has incorporated cultural activities into its facility and care as a way to honor the Alaska Native residents and make them feel more at home. The foundation of these activities came from knowing that culture is important to their health and wellbeing and realizing the importance of establishing and building rapport. Social worker Don Thibedeau collaborated with Dr. Jordan Lewis to develop a care manual that describes the Denali's Center's work; this manual is being used throughout Alaska. (Lewis & Thibedeau, Activity manual to honor Alaska Native cultures and traditions in care facilities, 2018)
- Leave of Absence program: This program of the Denali Center supports elders to visit their home villages – addressing the fear that people go away to die and never come home. The Leave of Absence program has allowed residents to return to their home communities for memorial potlatches, holiday events, family celebrations, tribal meetings, subsistence activities, or an extended weekend visit. A volunteer or trained staff that is able to attend to physical needs accompanies an elder on his or her trip home. Being able to return to the village removes the stigma of being a "sick person" or patient, which often associated with long-term care facilities in urban Alaska.



Teresa Holt (from an experience as the Alaska Long-Term Care Ombudsman)

At a site visit to Kotzebue, I went on a fieldtrip with two Alaska native elders with significant dementia. In the car they were not responsive to verbal or visual input. We arrived at fish camp, staff assisted them to a bench. Fish caught in the net. Staff brought fish up for the elders to see and touch. Another elder set up a table near us and began cutting fish. From the moment the elders exited the vehicle, you could see them "awaken". Pointing, saying words, talking on the car ride back. By the time we returned, one elder was inviting me to visit him in his village to meet his dog team.

GALENA ELDERS' HOME

The Yukon Koyukuk Elder Assisted Living Facility in Galena also integrates culture into all decision-making. Agnes Sweetsir, Elder Home Administrator, shared "We started by sitting down with our board and deciding what kind of a home we wanted for our elders – mission and philosophy with specific values that were important. We keep those lenses on, everything we do runs through that."

She shared there are three key things that have helped create a culturally integrated environment in the home:

- Local culture: Incorporating art, music, and traditional foods from the region. She shared that the river is also an important cultural element: "So much of their personal and community stories are associated with the river."
- Local hire: Hiring people from the community who respect their elders.
- Community-wide education: The elders' home partnered with Alzheimer's Resource of Alaska on trainings so if an elder with dementia was wandering, community members would know how to provide supportive assistance.

It really helped to increase the capacity of people knowing about dementia – what to watch out for and not to take things personally. It was helpful for people to understand that they are no longer the people we knew but still human beings with human needs.

— Agnes Sweetsir, Administrator, Galena Elders' Home

TRADITIONAL FOODS

Traditional foods provide a sense of purpose and identity. The effort to integrate traditional foods into long-term care facilities was spurred by Val Kreil, former administrator of Maniilaq's Utuqqanaat Inaat. This model has become used in many communities in Alaska and the federal Center for Medicaid and Medicare Services (CMS) has now identified this as a best practice.

OTHER RESOURCES

- The Alaska Native Tribal Health Consortium (ANTHC) published a resource: "[Traditional Foods Guide for the Alaska Native People](#)" which includes stories, recipes, and nutritional information.
- There are also cookbooks produced by village-based organizations such as "Enaa Sebaabe. The Best of Huslia" and "Baabe Leeneyh (Delicious Food), Yukon Kuskokwim Elder Assisted Living Facility." Aleutian Pribilof Island Association published [Qaqamiiġuġ: Traditional foods and recipes](#), available from the Tribe and also on Amazon.

Traditional foods are spiritual foods – critical to the care and well-being. A fish head can be like an anti-depressant.

We have found that traditional comfort food provides more nutritional value. As one of our residents so eloquently put it, "they call it traditional food but for us it's spiritual food." We make every effort and have lots of partnerships with community members to provide their native foods and have taught our cooks to cook things like moose head soup, fish ice cream, wild berry pudding, fish heads, beaver, spruce chickens, etc.

— Agnes Sweetsir, Administrator, Galena Elders' Home



NEW RURAL ELDERS' HOMES: NATIVE VILLAGE OF UNALAKLEET

Until very recently, elders with a diagnosis of ADRD in Unalakleet would stay in the village as long as they could but eventually would have to go to a larger community, typically Nome or Anchorage, when their needs could no longer be supported at home.

Unalakleet decided they wanted to build an assisted living facility so elders could age in place. The pre-development work through the Foraker Group was very helpful. Tribal members from Unalakleet visited elders' homes in Galena and in Wasilla to help in creating their vision of what they wanted locally. Once the planning was completed, then "the real grant-writing began. It's very complicated to put a project like this together," shared one of the planners.

The Native Village of Unalakleet Elders' Home, formally named Ikayuqti (Helping People), has 10 private rooms, each with an accessible bathroom. These rooms open up into a communal living room and dining room for the elders who are no longer able to reside in their homes, but who do not qualify for a skilled nursing level of care. This home enables elders to be close to home, family, friends, and community.

Caregiver support

THE CAREGIVER CONNECTION PILOT

[The Caregiver Connection](#) is a pilot launched by Senior & Disabilities Services in partnership with Alzheimer's Resource of Alaska (ARA) and the Anchorage Aging and Disabilities Resource Center (ADRC). The goal of this project, which started engaging with family caregivers in February 2020, is to improve supports for caregivers so that individuals with dementia can remain in their homes longer and experience better quality of life. The project incorporates use of an evidence-based caregiver assessment tool - Tailored Caregiver Assessment and Referral (TCARE®).

The ADRC staff uses the Person-Centered Intake (PCI) screening to identify caregivers that may be appropriate for the Caregiver Connection Program. The ADRC then makes referrals to ARA for the Caregiver Connection Program (CCP) Screening. ARA also receives referrals from outside sources (providers, advertising, etc.). Once the CCP screening is performed, caregivers meeting the criteria for a high level of caregiver burden will have a complete assessment and then be provided a limited service plan based on the assessment results and the caregivers' identified needs. While the most often requested service is respite, caregivers also have access to additional supports such as training, coaching, counseling and support groups, to name a few.

In addition, all direct support professionals (DSPs) providing services through the CCP program must successfully complete an eight-hour dementia training for frontline staff. This aspect increases capacity of DSPs with dementia care knowledge.

This is a shift in the way the need for state services is typically determined; historically the need for service is based on the level of care of the person with ADRD, not the level of burden as described by the caregiver.

Like any pilot program, we have had our share of challenges. And of course COVID has made it even more challenging. That being said, absolutely YES I think this is working. Not only do caregivers with a high level of caregiver burden receive additional supports through the CCP program, everyone referred has access to ARA's resources and services.

— Kay Papkristo, Education Director, Alzheimer's Resource of Alaska

Training

The 2014 Roadmap cited developing a workforce trained in dementia care as one of its six goals, five of the 11 urgent priorities addressed workforce training. There has been significant progress since 2014. This section highlights several areas of success to build upon.

TEEPA SNOW AND THE POSITIVE APPROACH TO CARE™

[Teepa Snow](#) is renowned worldwide for her approach to dementia care. Her training is based on many years of experience, both personal and professional. Her strengths-based approach and experiential method of teaching skills resonated with Alaskans during her first trip in 2013, which led to an ongoing relationship.

Alzheimer's Resource of Alaska committed to supporting service providers by securing funding to provide Positive Approach to Care™ certification courses, developed by Teepa, a regular basis and to establish in-state trainers. Over 100 Alaskans have completed the Positive Approach to Care™ certification. There are a few dozen independent Positive Approach to Care™ trainers and engagement leaders in Alaska as a result of ARA's initial collaboration. There is an established Alaskan Positive Approach to Care™ group that meets with mentors on a regular basis to discuss best practices and challenging situations. ARA's vision is to maintain a Positive Approach to Care™-certified staff member in every large facility across the state. Pam Kelley, ARA Executive Director, shared that PAC™ isn't a curriculum – it's a method for making culture change operational.



The Magic of Teepa

The real key to Teepa Snow's style: she teaches by channeling the actions of someone in one of the dementia states.

She will slip into this role and then engage an audience member. She might swear at them – “get the hell away from me” - or grab their cell phone. And then she talks through the why of it and provides techniques – “This is how you might approach this”. She turns the moment into an experience of engagement instead of conflict and stress. Her approach allows us in the field to have that wisdom on the fly ... It's called “Teepa Magic”.

CNA DEMENTIA SPECIALTY APPRENTICESHIP TRAINING

The Pioneer Home system launched an apprenticeship program for certified nurse assistants (CNAs) focused on dementia in 2016. This opportunity is currently available in Alaska only through the Pioneer Homes. The program is optional; the CNA must be employed by a Pioneer Home for a year before applying. The Dementia Specialty Apprenticeship encompasses approximately 2,000 hours of on-the-job learning and 139.5 hours of related instruction, including 39.5 specific to dementia – many of the courses include information on the Positive Approach to Care™ model. (Donlon & Williams, 2018)

Approximately 50 CNAs have completed the apprenticeship or are currently enrolled, which is about 20% of the CNA employees.

This program has provided confidence and essential skills to enhance the work performance of experienced CNAs working with those who have a diagnosis of dementia. The CNAs' newly gained knowledge and practice of skills enables them to engage in a more positive way with older adults, improving the quality of life for older adults and making performance of and receiving assistance with ADLs easier. The apprenticeship relies extensively on Teepa Snow's Positive Approach to Care which has been shown to improve quality of life and quality of care.

— Heidi Hamilton, Director, Alaska Pioneer Homes

VETERANS ADMINISTRATION RURAL INTERDISCIPLINARY TEAM TRAINING

The Veterans Administration Rural Interdisciplinary Team Training program delivers distance-delivered training on geriatric care, including but not limited to identifying cognitive impairment and referring to a diagnosing professional. This model has been adapted for tribes and has been delivered in Alaska for team training. This program offers CEs for physicians, physician assistants, social workers, and nurses. Since 2017, this training has been delivered in Unalaska, Anchorage, Fairbanks, the Kenai Peninsula, Nome, and Juneau. Since the COVID-19 epidemic, training has been available through webinars. (VA Geriatric Scholars Program, 2019)

Using technology in service delivery

Technology is increasingly developing opportunities to support the health, safety and independence of people with ADRD. Different types of technology include assistive robots, movement sensors (for example detecting a fall or if someone has wandered away), and smart home technology (like Alexa or Echo). COVID has greatly increased adoption of technology, especially telehealth.

ASSISTIVE TECHNOLOGY OF ALASKA (ATLA)

[ATLA](#) is the state's Assistive Technology Act vendor and provides consultation and equipment to people with ADRD.

Examples of assistive technology ATLA offers:

- Amazon Echo Show: a digital companion that includes options like setting reminders, calling friends and family members or answering questions like the time of day. Caregivers can set it up so they can remotely drop in at any time.
- BedAlarm Safe Wander and Gateway: sends a beeping alert to a caregiver as soon as the sensor detects the user is getting up.
- MyNotifi Detection Wristband: alerts family and friends if the user falls.

ATLA provides ongoing training and presentations to organizations on emerging assistive technology as well as Individualized assessments.

HOME MODIFICATIONS FOR AGING IN PLACE (HOMEMAP)

[HomeMAP](#) is an innovative tool originally developed by the Southeast Alaska Independent Living Center (SAIL). It is an assessment tool used by a trained specialist and evaluates the residential setting to identify environmental modifications – like ramps and grab bars – as well as assistive technology options that will increase accessibility and safety of the person with ADRD living in the home.

SAIL created the original HomeMAP when they had two staff members with previous careers in construction. As independent living specialists, SAIL was aware that most people who are aging or living with a disability want to

live independently in their own home as long as possible. The pairing of independent living and home accessibility modification knowledge was intentional, as a holistic approach best serves the comprehensive needs of people within their specific setting. A second important intent is to keep the consumer in the driver's seat in making choices.

Expansion of the HomeMAP was identified in the 2014 ADRD Roadmap. The HomeMAP is now being used across Alaska; there are trained assessors at SAIL offices, Independent Living Center (Kenai), Arctic Access and ATLA. In FY20, approximately 85 people received a HomeMAP statewide.

HEALTH TIE (TESTBED FOR INNOVATIVE ENTERPRISES)

[Health TIE](#) is an Alaska-based nonprofit focused on connecting service providers and organizations with emerging health technology start-ups and facilitating pilot projects. It is difficult for health and human service providers to stay on top of emerging technologies. Health TIE assists by staying informed about the needs of Alaska providers, including ADRD providers, and facilitating connections with promising start-up companies.

While Health TIE is a fairly new organization, it has already introduced several new technology opportunities in Alaska including Zinnia TV, "gently paced videos" that are designed specifically for people with mid-to late stage dementia. Health TIE introduced Alzheimer's Resource of Alaska to Zinnia TV's founder; ARA is now offering Zinnia TV as a resource and collecting feedback to help Zinnia TV improve its product.



Allyson Schrier, Founder, Zinnia TV

My husband was diagnosed with dementia in his mid-40s. He lived at home until his care needs exceeded my abilities. On visits with him, it was a challenge to witness how frequently the television was used as a babysitter. On the screen would be whatever channel the tv was set to. I would see people sleeping, getting agitated, or looking around. And I started wondering whether there was television programming specifically intended for people like my husband; people who could no longer track a plot, who had a hard time telling fiction from reality, who were challenged to process rapidly moving dialogue or images.

Veteran Directed Care Services

The Veteran Directed Care (VDC) program was developed by the federal Veterans Health Administration and the Administration for Community Living to offer veterans and their caregivers greater access, choice and control over the long-term services and supports that help veterans live at home and remain a part of their communities. The VDC program increases access to home and community-based services to meet the growing demand of veterans who prefer independence at home over living in a nursing facility.

The VDC program provides veterans with opportunities to self-direct their services and continue living independently at home. Eligible veterans, or their designee, manage their own flexible budgets, decide what mix of goods and services best meet their needs, and hire and supervise their own workers. Through an options counselor, the Aging and Disability Resource Centers provide information and assistance for enrollment into the program, arrange fiscal management services, and provide ongoing counseling and support to veterans, their families, and caregivers.

Currently there are three organizations in Alaska operating VDC programs: Southeast Alaska Independent Living providing services throughout Southeast Alaska, Independent Living Center serving the Kenai Peninsula, Kodiak Island and the Valdez/Cordova census area communities, and LINKS Mat-Su, serving veterans living in the Mat-Su region.

Program is a Godsend ...

Dad served in the Army during the Korean War. He is 85 now and has diabetes and dementia. He was living with my sister in another state but after KANA (Kodiak Area Native Association) added VA services, he moved in with us. I had to cut back on work to stay home with him. VOICE (VDC program) has been a godsend financially. VOICE pays me to take care of him. I pay his bills, take him to the doctor, make sure he's OK. If family could not take care of him and he had to be in a nursing home, he would be dead by now.



A Lifesaver for Us

Joe Hotch is a 90-year-old Alaskan Native Elder and Tlingit leader that lives with his wife in Haines, AK. Joe served our country in the Army. His wife Georgiana has been Joe's primary caregiver as his health has begun to decline in recent years. They needed to find additional in-home care to meet Joe's needs. "The VOICE program has really, really lightened my stress about how Joe's need will be met. I was really worried about his safety when I had to go back to work and now I'm not. This program has been a life saver for us".

Today's Urgent Needs

The core planning team for the ADRD Map recognized the value of a dynamic and ongoing process to address the needs of Alaskans impacted by ADRD. Today's priorities might not be the priorities of tomorrow, or over the next ten years. These are the current urgent needs shared by stakeholders.



Public Awareness

Public awareness of ADRD has multiple facets including addressing stigma so caregivers will reach out for support as well as creating “dementia-friendly” communities and promoting early diagnosis and preventive behaviors.

The National Alzheimer's Association advocated for and successfully passed legislation called the “Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act”. This act authorizes funding for states to implement public awareness campaigns.

Examples of public awareness campaign activities include:

- Communicating the scope and magnitude of the problem
- Promoting the benefits of early detection and diagnosis
- Educating the public about the cause and nature of the disease
- Encouraging community activities that will educate Alaskans about the importance of seeking a diagnosis

HEALTHY BRAIN PRACTICES

In the past the general thinking was that ADRD just happened and there was nothing to do about it. By and large Western medicine addressed symptoms. Now evidence supports modifying risk factors to delay or reduce severity of dementia. Health diet and lifestyle, cognitive exercises, oral health care, and positive social engagement are some of the ways to address risks.

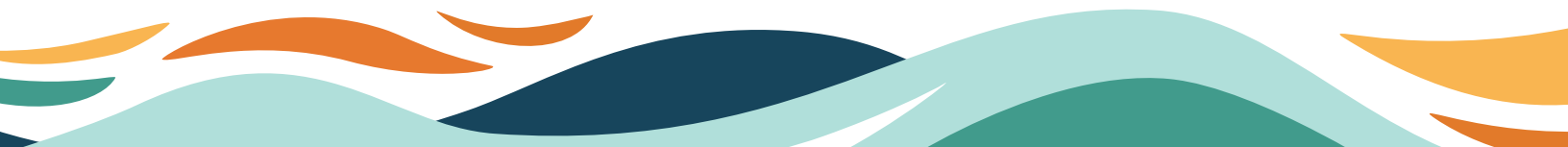
Investing in public awareness around these practices, which coincide with other public health issues, will save money in treatment and services in the future.

- Mediterranean and DASH Diets are well-documented as a protective factor (Gómez-Pinilla, 2008) (Baranowski, Marko, Fenech, Yang, & MacPherson, 2020) (Gardener & Caunca, 2018) (Zamroziewicz & Barbey, 2017) (Lange, et al., 2019)
- Together, 12 modifiable risk factors account for around 40% of worldwide dementias (Livingston, et al., 2020): education, hypertension, hearing impairment, smoking, obesity, depression, physical activity, diabetes, social contact, alcohol consumption, traumatic brain injury, and air pollution.
- Culture and humor - Dr. Jordan Lewis has documented the value of laughter as a protective factor (Lewis J. P., The Importance of Optimism in Maintaining Healthy Aging in Rural Alaska, 2013)
- Good cardiovascular health makes a difference. The Honolulu-Asia Aging Study, funded by the National Institutes of Health and the Alzheimer's Association, was one of the first studies to show that untreated hypertension in middle life was associated with a significantly higher risk of developing dementia in later life for Japanese American men who participated in the study. However, if the hypertension was adequately treated, this increased risk was mitigated. It was also demonstrated that higher physical activity like walking was associated with a lower risk of developing dementia over a 6-year follow-up period (Gelber, Launer, & White, 2012)
- Good dental health is possibly linked with good brain health. Periodontal disease was modestly associated with cognitive impairment and dementia in a community-based cohort (Dhana, Evans, Rajan, Bennett, & Morris, 2020)

COORDINATED DATA COLLECTION

Alaska currently has no consistent method of counting the number of people being diagnosed with ADRD. Prevalence data is estimated, based on the number of Alaska residents in certain age categories and ADRD trends.

Tracking this information has multiple challenges ranging from stigma to training to funding. As a consequence, typically the diagnosis is made at a later stage and may not appear in the legal medical record at all. While a formal



diagnosis does not, by itself, result in removing an individual's ability to make his or her decisions, there is concern that it can be used in support of seeking guardian or conservatorship. Unfortunately, this delay or lack of diagnosis impacts access to important resources, delays planning and limits accurate information on ADRD prevalence.

There is the perception that once you formally say as a physician that someone has an ADRD diagnosis, you also formally remove their ability to make their own decisions, spend their own money, drive their car or choose to live where they want.

— Dr. Steve Tierney, Senior Physician for Information Management, Southcentral Foundation

Training

TRAINING FOR PRIMARY CARE DOCTORS

Many health care providers across the state do not have the training they need to diagnose cognitive impairment and dementia. The diagnosis is the ticket to support. Most states have some sort of geriatric training center that provides education for primary care providers and caregivers, and Alaska does not.

Doctors can be reluctant to diagnose dementia, and yet, as stated above, this hesitation slows access to resources and delays planning.

In addition, medical providers need information regarding available resources and options like Supported Decision-Making, which provides assistance with making decisions without taking a person's rights away.

Medical providers often don't understand the difference between various service options, how to qualify, how to apply, and what they provide. Don't offer resources that the person doesn't qualify for.

— Webinar Participant

Dementia is a primary care diagnosis; the local health care provider should be able to make that diagnosis. It is not a good excuse for a primary care physician to say I don't know how to do this.

— Dr. Bruce Finke, Elder Health Consultant, Indian Health Services

TRAINING FOR FIRST RESPONDERS

There is no consistent education and training in Alaska for frontline workers and first responders like public safety officers. This poses a barrier to accurate identification and diagnosis, as well as to appropriate response in an emergency.

My family had an experience where a state trooper threatened to put my 80-year-old 100-pound mom in handcuffs. I think a better trained state trooper would have figured out a better way to de-escalate the situation.

— Webinar Participant



Workforce

The direct support workforce in Alaska is struggling to meet needs in two ways: not enough workers and the existing workers don't have the necessary training.

First, there is not a consistent training standard for people providing direct support. Assisted living regulations require a certain number of hours each year of continuing education but training specific to ADRD is not required. Home and community-based services, including waiver, personal care services and home health have no training requirements beyond basic health and safety such as medication administration, first aid/CPR and universal precautions. The most structured direct support training curriculum is the Certified Nurse Assistant. This is a certification regulated by the State of Alaska. It does not include dementia training.

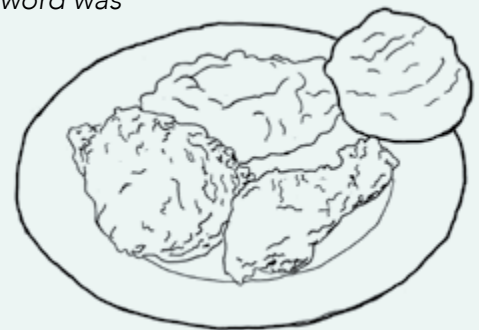
Lack of relevant training affects both the quality of support provided to the person with ADRD and the job satisfaction of the worker. A major factor in high turnover in the direct support field is lack of training; people don't feel successful and leave the field. Lack of staff retention is a serious issue in a field that is struggling to hire enough workers to meet basic needs. Inadequate compensation also significantly impacts retention in this field.

Population changes in Alaska are exacerbating the workforce issues. The population between ages 18 and 64 is steadily decreasing – there were 22,654 fewer working age Alaskans in 2019 than in 2013. (State of Alaska Department of Labor and Workforce Development, Research and Analysis Section, 2020) In 2018 there were 15.9 potential caregivers aged 40 to 64 for every senior over 80. By 2030, this will decrease to just 7 potential caregivers for each senior over age 80. Nationwide, in 2018, the ratio of potential caregivers to seniors was 8.6 to 1. (State of Alaska, Alaska Commission on Aging, 2019)

In some regions, the limited services that are available are under-utilized because of this workforce shortage.

Know Your No's

The assisted living home called. Mom was refusing food. When Jim visited his mother, her first word was "no". He quickly realized every word was "no". When caregivers brought in food: no. They took her tray away. Jim knew his mother's lifelong love of greasy fast food. He ordered the works; put the plate of fried chicken, mashed potatoes and a soft biscuit before his mother. "No" she said. He didn't take the plate away. He served up his own plate and began eating beside her. Shortly, she began eating from her plate, and sampling his own as well. Yes!



There is always a need to look at the use of antipsychotic medications for this population. I prefer to use the term 'distress' to 'behaviors' as we discuss the need for these drugs, but at the heart of most emergency antipsychotic drugs being administered is simply not understanding what is causing the resident distress.

— Webinar Participant

Resources for people with ADRD & family/informal caregivers

Alaska's success in better meeting the needs of people with ADRD relies on informed, supported family members and other informal caregivers. Informal (unpaid) caregivers often include non-family members such as friends, neighbors, church community, etc. Accessing community services can prevent or delay the need for out-of-home care.

Family/informal caregivers may not know what services are available or have difficulty navigating the service system while trying to provide care.

Senior and Disabilities Services is implementing a public media campaign in 2021 to increase awareness of the Aging and Disability Resource Centers. These six centers are located throughout the state and can offer information and support for caregivers and people with ADRD.

Family/informal caregivers will always be an important part of the support system for people with ADRD. They are strengthened by having easily accessible information that includes what to expect, where to go for help, and how to plan for the future.

Feedback from webinar participants:

- Statewide, there are limited options between diagnosis and acute care services/memory care facilities.
- There is a lack of awareness of the Aging and Disability Resource Centers and available services.

Financial planning

There is a large gap between the cost of care and the financial resources that are needed to pay for care, whether home and community-based or nursing home care. Nursing home care is particularly costly and Alaska is by far the most costly in the country (Genworth Financial Services, 2020). The publicly funded system of care is oriented to people who are Medicaid-eligible and the cost of care far exceeds the value of long-term care insurance. Families find themselves having to liquidate assets in order to be financially eligible for assistance in accessing care. While Native elders may worry about having to liquidate Native land allotments or stock in Native corporations, these are specifically excluded by state regulation as assets to spend down (<http://www.akleg.gov/basis/aac.asp#7.47.355>). Most other assets would have to be liquidated.

Alaska offers state programs to cover costs for seniors and people with disabilities, including ADRD. These are geared towards low-income individuals who have severely limited assets and income. While tribal health organizations provide care to elders, there is no special funding for Alaska Native elders. Services are provided based on insurers, primarily Medicaid.

Long-term care insurance policies are held by slightly fewer than 30,000 Alaskans, the vast majority through the Alaska State Retiree Long Term Care program. (State of Alaska Department of Commerce and Economic Development, Division of Insurance, 2019) These policies offer an off-set to the costs of care, if a person meets qualifications.

Depending on the plan, the off-set can be quite small. The remainder has to be covered out of pocket. A detailed description of long-term care insurance in Alaska is found in Appendix B: Long-term care insurance in Alaska.

Health insurance and Medicare can cover some costs of facility and home-based care, depending on health needs. Alaska's major insurers have an interest in keeping seniors healthy and preventing AD/DR. These insurers are Premier Blue Cross, Humana, and UnitedHealthCare.

The need for out-of-home long-term care can be a catastrophic unexpected event. The reality is that a significant number of Alaskans will not qualify for Medicaid or VA-funded services. Currently there is little information on the cost of care or how to plan for it. Few people have financial planning in place in advance. This includes people who have assets they would never consider selling, such as a Bureau of Indian Affairs allotment or family home/homestead. Thousands of Alaskans have paid into retirement plans and purchased long-term care insurance only to discover too late that the insurance does not cover the cost of care. Often family caregivers are left with difficult decisions.



Couldn't Use Insurance

My relative worked in public service and was a PERS retiree. She paid into long-term care Insurance for years, but it was the Bronze Plan (pays \$125/day). There was no place to use long-term care insurance where she lived even so, and she had to move for care. The only senior housing was for low-income people, she didn't qualify. She ended up living back home with me. We paid out of pocket for help for me so I could sleep a couple of nights a week.

Planning Ahead

My husband and I are young, active, athletic Alaskans. We know we take risks in our sports. We researched long-term care policies so that if one of us were injured, we would be covered. Our employers don't offer that insurance. We keep it up, because we will stay active. We budget it into our monthly expenses.



Grateful for Investment

I am a younger Tier 1 PERS retiree who bought long-term care insurance. I'm glad I have it. My mother was diagnosed with AD/DR recently and long-term care insurance is helping us pay for her care. It is good that she is in the Lower 48 already, because Alaska's costs for long-term care are very high.

Service access and options

As the number of people with ADRD increases, funding for services has remained flat. State grant-funded services have not increased for the past five years. Tribes have advocated for Indian Health Services funding for eldercare services, but despite authorization for services, there has been no funding for tribal health agencies to pay for these services.

In addition, the limited home and community-based services that are available have rigid definitions and eligibility requirements. Promising practices such as the Veteran-Directed Care program and the Caregiver Connections pilot are opportunities to build on.

We are moving folks to assisted living homes at an alarming rate for average of over \$50,000 a year yet all the family needs is a service we can't offer because the person doesn't fit in the funding definition box. We are spending MUCH more money in ALH support than trying to keep people in their own homes. This is not a current priority. We don't ask clients what they need we tell them what we can offer. It is backward and when we ask them what they need to stay in their own home we have to tell them there is no service for that.

— Webinar Participant

I have never had a family or client tell me I can't wait to move to an ALH. They want to stay in their own home but I can't make that happen with current service definitions and limits.

— Webinar Participant, Care Coordinator, 20 years' experience

I work in an acute care facility and we often see late stage patients without family or support, or with family who can no longer support the patient. Most concerning are those with late stage who are unwilling to allow us to coordinate a safe discharge plan. We have no legal structure in place to provide supportive care for those who refuse it. Lack of supports and services not only puts patients in dangerous situations, but really makes it difficult for health care providers who work with these patients repeatedly as they decline without support.

— Webinar Participant

RURAL NEEDS

Approximately 30% of Alaskans live in rural communities (Rural Health Information Hub, 2020) Rural communities, especially remote small villages, often have limited capacity for community development planning and funding. In many communities, there may be one paid employee, often a tribal administrator, that takes care of everything. This includes answering the phones and mail, taking minutes at council meetings, and managing problems that arise.

While communities want places for elders to age in place, they are often forced to leave their village for a larger community with an assisted living or long-term care facility when an elder's care cannot be supported in the home environment.

Possible solutions to development of rural elders' homes and services:

- Provide support with planning and fund development to community leaders

- Address challenges with tribal state relationships. For example, to administer state grant funds like a senior in-home grant, the tribe must waive their right to sovereignty which can be a difficult decision for a tribe to make
- Simplify grant reporting requirements as much as possible
- Allow flexibility in services and funding to accommodate rural settings

"It's really hard on the villages. People want to help the elders but they might not have the management skills that a grant requires. Or there might just be one person who has to take care of everything ... a lot of them get overwhelmed."

— Rural Program Administrator

CAPACITY TO ADDRESS PEOPLE WITH COMPLEX CARE

For purposes of this document, complex care is described as people who are potentially harmful to themselves or people around them because of aggressive or assaultive behavior. This behavior may have manifested as a result of the onset of ADRD. Or a person may have a history of mental health issues, a traumatic brain injury or PTSD and a diagnosis of dementia increases the difficulty of and need for care. The Alaska Psychiatric Institute (API) or an out-of-state placement is often the only option. In fact, there were 29 ADRD admissions to API in FY20. (Correspondence, API Public Information Office, 11.3.20 and 12.1.20)

The 2014 Roadmap identified this need and defined several possible strategies including tiered reimbursement rates based on acuity, increased use of the Complex Behavior Collaborative, and incentivizing the development of crisis respite beds to provide short-term specialized treatment settings where people can stabilize behaviors and then move to lower level care settings.

Hope Community Resources partnered with the state on a pilot project starting in 2017 to create a specialized setting with the goal of transitioning people out of the API, with limited success. Six people have transitioned out of API with the support of Hope but there continues to be systemic barriers. Although there are many people in need, the referrals have been minimal and fraught with issues of eligibility, according to Michele Girault, CEO of Hope Community Resources. In addition, while services are less expensive than API, there's been an ongoing struggle with funding. Workforce has also been a challenge - finding staff with the necessary skills to support the high needs of people in this program.



A Home at Last

She's lived in that house for two years now, the longest she's lived in one place in many years. Who is she? Today - an elder with dementia. Before the dementia, a person with lifelong mental health needs. Aging and dementia came with increased agitation and at times, broken bones, which led to many hospitalizations, multiple assisted living homes, and eventually API. A pilot with Hope Community Resources created an environment with specifically trained staff 24 hours a day, guided by an in-house behavioral health specialist, that has made all the difference. And now she has a home.

What's Next? A Call To Action

Next Generation Alaska Dementia Action Collaborative

An ongoing workgroup will support and advance the work of the many organizations and people who comprise the system of financing and care. It will provide mutual accountability and an opportunity for advocacy where needed.



People with ADRD, their families and caregivers find major gaps in addressing complex and evolving problems and navigating solutions. Services and strengths are not always easy to identify, and financing for services is not always aligned with individual need. Alaska has a number of successes, excellent services, promising practices, and coordination—and these can be strengthened, expanded, and elevated. Where we have strengths, we can build on them. Where we have gaps, we can address them—together.

The Next Generation Alaska Dementia Action Collaborative will:

- Ensure we keep sight of and make progress on our goals
- Provide mutual coordination and accountability across sectors and interests
- Build on and elevate strengths of Alaska's rural village/rural community solutions
- Advance and elevate Alaska's other promising and best practices including use of telehealth and other emerging technology
- Coordinate data collection, funding opportunities, and sharing best practices

We envision that each year the Collaborative will develop an annual plan that includes realistic goals, strategies and measurable outcomes, guided by Alaska's 2030 Vision and Map. A workgroup will meet regularly, ideally with the support of a dedicated facilitator.

In order to achieve the goals of this plan, the work of the next decade will require a coordinated effort. Through discussions with the core planning team, the following best practices have been identified to guide the process. These practices, along with this document's goals and principles, will create a framework to drive forward the strategic priorities.

COMMUNITY DRIVEN: PROGRAM DESIGN COMES FROM WITHIN THE COMMUNITY

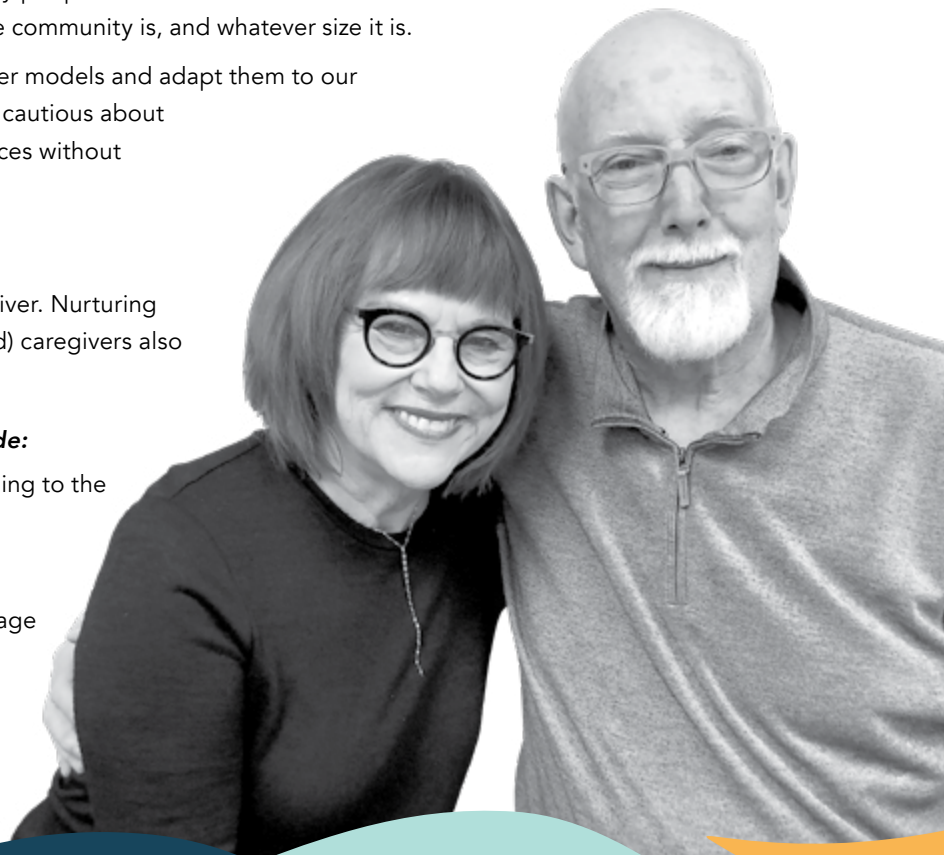
- Services are most successful when designed by people in their communities. Build on community strengths and assets, wherever the community is, and whatever size it is.
- Flexibility is important. We can learn from other models and adapt them to our Alaskan communities. However, we should be cautious about adopting and applying models from other places without adapting them to local culture and norms.

CARE FOR THE CAREGIVER

Care for the individual means care for the caregiver. Nurturing family/Informal caregivers as well as formal (paid) caregivers also nurtures the elders.

Key elements of supporting caregivers include:

- Dementia education. Knowing what is happening to the elder in the progression of their dementia.
- Support with problem-solving.
- Self-care. Caregivers need to be healthy, manage stress, ask for help, receive help like overnight respite so they can sleep through the night.



COLLABORATION OF BOTH PRIVATE AND PUBLIC PARTNERS

Services are provided by family caregivers, paid caregivers, religious communities, medical providers, assisted living facilities, nursing homes, and senior service agencies. Care for people with ADRD is funded by a blend of insurance, private pay, Medicaid, Indian Health Services funding and state grants. To advance care for all people with ADRD requires partnership beyond publicly funded agencies. Realizing the goals described in this plan will require increased investment in resources, services, facilities, and research. Collaboration that includes leveraging project resources and coordinating efforts will make dollars stretch further, with a greater impact.

A plan that doesn't acknowledge that there are costs is wholly aspirational.

— Webinar Participant

Navigating this process will not be easy. Just as the river is full of turns, each one bringing new challenges, adventures, and memories, there will be rough waters. With adequate resources, knowledge, and supports, the journey down the river will be smoother, the destination worth it. And we will all benefit.



Appendix A: Demographics of Older Adults in Alaska

Alaska population trends

In line with the aging trend, Alaska's 65-plus age group grew by 4,200 people in 2019, reaching 91,278, and is projected to top 136,000 by 2030.

According to Alaska Economic Trends (Hunsinger, Alaskans 65 and older: Our current senior citizen population and how it's changing, 2019), Alaska's senior population will continue to increase through this decade and peak in the mid-2030s. By 2035, Alaska Economic Trends predicts that the state will reach 138,000 seniors: just over 17% of the population.

The U.S. Census Bureau projects a smaller increase for the national population, but the number and percent of seniors in the Lower 48 are expected to increase through the 2030s and past 2045.

At the same time, Alaska's younger age groups continues to get smaller. The population between 18 and 64 decreased for the sixth year in a row, down nearly 5,000 people to 455,583. The 17-and-younger group decreased for a third year, by 2,400, to 184,146 total children. (Whitney & Brooks, 2020)

Living situations of Alaska's seniors: home-owners, renters, living with family

Eighty-two percent of Alaska seniors live in owner-occupied homes compared to 64 percent of Alaskans overall, and 18 percent live in rentals. Apartment-style assisted living isn't considered group quarters, so is considered rental. (Hunsinger, Alaskans 65 and older: Our current senior citizen population and how it's changing, 2019)

LIVING WITH OTHERS: MORE THAN LOWER 48

Just over two-thirds of seniors in Alaska live with family.

The average size of senior households is 2.1 people. This is similar to Alaska's larger average households in general, and a bit higher than for all U.S. seniors (1.9).

LIVING WITH AND CARING FOR GRANDCHILDREN: MORE THAN LOWER 48

Seven percent of Alaska seniors live with grandchildren. By comparison, 5% of seniors in the lower 48 live with grandchildren. In Alaska, 2% of seniors are responsible for the care of their grandchildren.

More than three-quarters of co-resident grandparents are under 65, however, and caregiving by co-resident grandparents decreases with age.

LIVING ALONE: FAR MORE THAN OTHERS IN ALASKA, BUT LOWER THAN LOWER 48

About 23% of Alaska seniors live alone, according to estimates from the U.S. Census Bureau's American Community Survey and reported by Alaska Economic Trends. By comparison, only 9% of state residents live alone. This is lower than the nationwide 26 percent. (Hunsinger, Alaskans who live alone: Demographics of single-person households, 2014)

NURSING HOMES, OTHER DORMITORY STYLE FACILITIES: SAME AS LOWER 48

Only 3% of Alaska's senior citizens live in "group quarters," which includes nursing homes and other dormitory-style living facilities. This is similar to the rest of the country. (Hunsinger, Alaskans 65 and older: Our current senior citizen population and how it's changing, 2019)

ASSISTED LIVING

Alaska Housing Finance Corporation conducted a survey of Anchorage assisted living facilities in Spring 2020. (McCall, 2020)

- 77% are single family homes with less than five beds. Medicaid is the most common payor, by far. Most are occupied up to 3/4 of space available; almost 90% support people with ADRD.
- 72% report they can meet the special care needs of residents with dementia (wandering, behaviors) - yet behavior was by far the most common reason for discharge.

Vulnerable population: Low income older women living alone

Most seniors who live alone are women (57%).

- Living alone is particularly common among poor women. Sixty percent of women aged 65 or more who were in poverty lived alone between 2008 and 2012.
- This is more than double the rate for male seniors in poverty, more than double the rate for all women 65 or older, and six times the rate of the overall population — also trends that hold nationally. (Hunsinger, Alaskans who live alone: Demographics of single-person households, 2014)

Vulnerable population: Older people with disabilities who live alone

Thirteen percent of Alaskans have a disability, and 34% of people who live alone have a disability. More than 70% of the population of people with disabilities was age 65 or older. (Hunsinger, Alaskans who live alone: Demographics of single-person households, 2014)

Veterans: large population, some VA resources

As of November 30, 2020, Alaska is home to over 67,719 veterans from all wars. (National Center for Veterans Analysis and Statistics, 2020) Anchorage is home to 30,240 and the Mat-Su Borough is home to another 10,900. Alaska has the largest percentage of veterans in the U.S. (Census.gov - (<https://www.census.gov/library/visualizations/2015/comm/percent-veterans.html>))

VETERANS ARE MOSTLY MEN

The majority of Alaskan (79%) veterans are male, regardless of age. (National Center for Veterans Analysis and Statistics, 2020)

VETERANS HAVE A RANGE OF DISABILITIES

Just over 19,000 Anchorage veterans received disability payments in 2017 (National Center for Veterans Analysis and Statistics, 2020): more than double than in 2012. (U.S. Department of Veterans Affairs, 2020). They receive care through the VA Medical Center in Anchorage.

Appendix B:

Long-term care insurance in Alaska

Alaska State Retiree Long-Term Care

Alaska's Public Employee Retirement System (PERS) comes with a long-term care insurance option, which the retiree must select immediately upon retirement. PERS offers four plans, with different monthly premiums and reimbursement rates for services.

Since the long-term care insurance plan began in 1987, there have been fewer than 1,200 claims. There were only 329 open claims in June 2019. (Rankin, 2019)

THE PLANS AND THE PEOPLE THEY COVER

The Bronze Plan is the oldest plan, and closed on 1/31/2000. 3,719 retirees enrolled in the state's long term care insurance plan before the year 2000; 4,971 Alaskans are enrolled in this plan. Most Bronze plan holders are presumably aged 70+, because they retired before 2000. It is not clear how many of these retirees could have dementia. These planholders are likely to believe that their long-term care plan will cover costs of care, but it will not.

THE PLANS COVER CARE RELATED TO DEMENTIA, BUT THERE ARE BIG GAPS

The Bronze Plan does not cover services needed because of cognitive impairment.

Most retirees hold Silver, Gold and Platinum Plans. The Silver, Gold and Platinum Plans differ in monthly premiums and coverage amount.

The Gold Plan includes simple inflation protection; Platinum includes compounded inflation protection. The Bronze and Silver Plans offer no inflation protection.

Some issues exist with the LTC plan for retirees with dementia:

- A large gap between the amount that the four plans pay for long-term care and the cost of care
 - The Bronze Plan pays \$125 per day in-state for nursing home care and \$75 per day out of state. For comparison, the cost of care in the nursing home in Nome is \$1,772.52 per day.
- Whether services required because of cognitive impairment are covered or not
 - Silver, Gold & Platinum cover services if have a cognitive impairment. Bronze does not cover cognitive impairment.
- Whether respite is covered or not

Table 1 Coverage by Plan Option

PLAN	# Retirees enrolled
Bronze	4,971
Silver	8,437
Gold	5,887
Platinum	2,910
TOTAL	22,205

Table 2 Year of retirement

YEAR	# Retirees enrolled
>2000	3,719
2000-2006	6,523
2007-2011	3,700
2012-2015	4,874
2017	943
2018	970
2019	1,476
TOTAL	22,205

(State of Alaska Department of Administration Division of Retirement and Benefits, n.d.)

Other Long-Term Care Plans in Alaska

5,159 people were covered by individual long-term care plans and 1,872 were covered by group long-term care plans in 2018.

INDIVIDUAL LONG-TERM CARE PLANS

In 2018, only 63 new individual long-term care policies were issued. 141 were terminated. There were 4,835 plans in force at the end of 2018, covering 5,159 people. These individuals had policies for a collective 62,390 months with \$11,554,309 in policies paid. \$6,200,101 were made in payments. Table: Individual Health Insurance 2028 p. 45 (State of Alaska Department of Commerce and Economic Development, Division of Insurance, 2019)

GROUP LONG-TERM CARE PLANS

Only three new policies were issued in 2018, and 58 were terminated. 272 policies were in force at the end of 2018, covering 1,872 individuals. These individuals had had policies for a collective 22,770 months with \$2,154,602 in policies paid. \$1,367,728 were made in payments.

Table: Group Health Insurance 2028 p. 46 (State of Alaska Department of Commerce and Economic Development, Division of Insurance, 2019)

Health insurance and Medicare

Premiera Blue Cross is Alaska's largest health insurer, while Humana and UnitedHealthCare cover half the Medicare market. These providers have an interest in Alaska's seniors and people with ADRD.

- Premiera Blue Cross has 49.2% of the group health insurance market in Alaska, with 287,140 direct premiums written.
- Almost all federal employees in Alaska are covered by Premiera Blue Cross. 96.37% of federal employees have Premiera Blue Cross with 421,155 in policies.
- Humana and UnitedHealthCare split half the Medicare market, with 9,366 and 8,197 policies between them.

p. 48-50, Accident & Health Market Share 2018 (State of Alaska Department of Commerce and Economic Development, Division of Insurance, 2019)

Appendix C:

National Practices to Explore

In the United States, there are national, state, tribal, and local efforts to address the issues that people with dementia face, along with their families and communities. Each state has an aging plan that directs how the state will manage federal and state resources targeted towards elders, and most states have a plan for addressing ADRD. In preparing this Alaska ADRD Plan, we reviewed the states' aging plans for states with high populations of Native people as well as rural states. We also reviewed national plans and programs for people with ADRD.

The country has scattered approaches to diagnosing and serving people who experience dementia and their caregivers. Plans tend to focus on prevention, planning for and providing publicly funded care, and programming for support of caregivers. There is effort spent on workforce development, identifying risks of dementia, and diagnostics. Training for primary care providers—from community health aides to physicians—is sporadically available. Training for community members is sporadic and developed at the local level but rarely at the state level. State funding is flat. Caregiving models abound, but are not shared at levels accessible to all family caregivers, and family caregivers do not always know what their options are. Workforce is a constant concern.

Some notable themes come from the Healthy Brain Initiative: The road map for Indian Country; the National plan to address Alzheimer's Disease; and selected state plans listed in Appendix C: Bibliography and References

We identified programs that could be useful to Alaska in expanding our system of services:

Dementia Friendly America

[Dementia Friendly America](#), a national program of training everyone in the community about dementia, is used in hundreds of cities and tribes across the United States, but not yet in Alaska. This program involves a four-part training offered in the state by a statewide, regional, or local lead. The philosophy of this program is that dementia is a community issue that must be addressed at the community level, and that every part of the community has a role in fostering meaningful access to and engagement in community life for people living with dementia and their families. An informed community makes for more successful community life.

DEMENTIA EDUCATION IN SCHOOLS

The Red Lake Nation of Minnesota indigenized the Dementia Friendly America curriculum, and took it one step further. The Red Lake Nation recognized the growing number of community members with ADRD, and that many grade school children serve as a caregiver after school for the person living with dementia in their home. In response to this growing concern, the Tribal Nation developed a training and education program for its third grade classroom where a community member provides a presentation on ADRD, asks questions, and educates the students on the basics of ADRD so they better understand what is happening to their family member, know how to recognize the behaviors, access community resources, and provide support. In addition to educating students, it reduces the fear around aging and ADRD for these students.

Veterans Administration: REACH Program

REACH – Resources to Enhance Alzheimer’s Caregiver’s Health is a Veterans Administration program that is now working with other agencies including the Indian Health Service to develop a coaching model to support caregivers. (U.S. Department of Veterans Affairs, 2020)

Washington State’s NextGen Workgroup & Resource Guide

The State of Washington published a state plan in 2016 which included development of a “next generation workgroup,” embracing the need to build new infrastructure to meet future needs (Washington State Alzheimer’s Disease Working Group, 2016). A progress report published in 2019 details impressive accomplishments of this group. This model inspired the recommended next steps in this document.

One of the outcomes of the Washington effort was a publication for people with ADRD and family caregivers that provides comprehensive information on what to plan for as well as local resources. Alaskan stakeholders have started discussions about developing a similar guide (Washington State Dementia Action Collaborative, 2016).

Appendix D:

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January 2021

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