Alaska’s Roadmap to Address Alzheimer’s Disease and Related Dementias (ADRD)

Presentation to the House Health & Social Services Committee
Alaska Commission on Aging & the Alaska Mental Health Trust Authority
March 3, 2015
Presentation Outline

• Background information about Alzheimer’s Disease and Related Dementias (ADRD)

• Overview of Needs Assessment Activities

• Goals & Recommendations

• Next Steps
Roadmap Core Team & Agency Affiliations

- Alaska Mental Health Trust Authority: Amanda Lofgren & Nancy Burke
- AARP Alaska: Ken Helander
- Department of Health & Social Services, Senior and Disabilities Services: Lisa Morley & Duane Mayes
- Alzheimer’s Resource of Alaska: Karl Garber
- Department of Health & Social Services, Division of Pioneer Homes: Vickie Wilson & Ken Truitt
- Office of the Long Term Care Ombudsman: Teresa Holt & Diana Weber
- Department of Health & Social Services, Division of Public Health: Jean Findley
- Department of Health & Social Services, Division of Behavioral Health: Albert Wall & Reta Sullivan
- Alaska Commission on Aging, Denise Daniello
Alaska’s Roadmap to Address ADRD

Mission

• To improve public awareness, promote prevention and early detection, increase access to long-term services and supports, improve availability of safe, appropriate housing, and increase caregiver supports for all Alaskans with ADRD.
What is Alzheimer’s Disease and Related Dementias (ADRD)?

Alzheimer’s disease is the most common form of dementia, caused by the death of brain cells and the atrophy of the brain.

Other more commonly known related dementias include vascular, mixed dementia, Parkinson’s, and Lewy Body dementia.

Symptoms typically associated with ADRD include:

• Loss of memory and language ability
• Loss of balance and thinking abilities
• Changes in personality and behavior

There is no known cure or mechanism to slow progression.

Source: Alzheimer’s Association
Who does Alzheimer’s affect?

Alzheimer’s Disease and related dementias most commonly affect people over the age of 65, although approximately 4% of diagnoses are in younger people aged 30-64.

Source: Alzheimer’s Association, 2012 letter on younger onset
Projected Alaska Senior Population 2014 - 2042

Alaska Population Projections 2012 to 2040, Department of Labor and Workforce Development, State of Alaska, 2014
Rates of Alzheimer’s Increase with Age

Alaska Alzheimer’s Prevalence Rates by Age

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

Note: Estimates do not include the related dementia that is not considered Alzheimer's.
Alaska Alzheimer’s Disease Prevalence, Ages 65+, 2014-2025

The above projections do not include persons with related dementias and those younger than 65.

Percentage Change in Selected Causes of Death in Alaska: 2000-2011

- Cancer: -22%
- Heart Disease: -37%
- Stroke: -41%
- Lower respiratory diseases: -19%
- Alzheimer's disease: 17%
- Diabetes mellitus: -27%

Needs Assessment: Family Caregiver Community Forums

Caregiver community forums were held in seven communities in 2012-2013 to understand the needs of individuals with Alzheimer’s disease and their caregivers.

<table>
<thead>
<tr>
<th>Forum Location</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anchorage</td>
<td>50</td>
</tr>
<tr>
<td>Juneau</td>
<td>15</td>
</tr>
<tr>
<td>Fairbanks</td>
<td>32</td>
</tr>
<tr>
<td>Homer</td>
<td>18</td>
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<tr>
<td>Soldotna</td>
<td>28</td>
</tr>
<tr>
<td>Kodiak</td>
<td>12</td>
</tr>
<tr>
<td>Mat-Su, Palmer</td>
<td>6</td>
</tr>
<tr>
<td>Total</td>
<td>161</td>
</tr>
</tbody>
</table>

Source: Alaska Commission on Aging, 2014
Needs Assessment: Family Caregiver Community Forums

Findings from Community Forums:

• 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.

Source: Alaska Commission on Aging, 2014
Needs Assessment: Family Caregiver Survey

"What is the most difficult challenge you face as a caregiver?"

- Creates a financial burden: 15%
- Interferes with my work: 15%
- Contributes to my health problems: 13%
- Limits personal time: 14%
- Does not leave enough time for my family: 10%
- Creates stress and makes me feel depressed: 18%
- Affects family relationships: 14%
- No difficulties: 1%
- Contributes to my health problems: 13%
- Interferes with my work: 15%

Source: Alaska Commission on Aging, 2014
Needs Assessment: Family Caregiver Survey

“Which support services do you or the person you care for use?”

~31% use Adult Day

~25% use Transportation + Support Groups

~23% use Personal Care Assistance and Respite
Needs Assessment: Behavior Risk Factor Surveillance Survey (BRFSS) & Perceived Cognitive Impairment

“Have you experienced confusion or memory loss that is happening more often or is getting worse?”

Percent of population with PCI by age

Source: Alaska 2013 Behavioral Risk Factor Surveillance Survey
Needs Assessment: BRFSS Survey - Perceived Cognitive Impairment & Health Condition

Percent of population with PCI by health conditions

Source: Alaska 2013 Behavioral Risk Factor Surveillance Survey
Perceived Cognitive Impairment & Daily Life

Impacts to daily life as a result of Perceived Cognitive Impairment

- Given up chores due to memory loss: 28%
- Cognitive impairment has interfered with social activities, volunteer and work: 32%
- Family has provided care as a result of memory loss: 25%
- Needs assistance with things like safety, transportation, household activities, personal care due to memory loss: 62%
- Frequent Mental distress*: 27%

Source: Alaska 2013 Behavioral Risk Factor Surveillance Survey
Alzheimer’s Disease & Related Dementia Prevalence within the State’s Long Term Services & Supports

Percent of recipients with ADRD by program

Source: Division of Senior & Disabilities Services, SAMS data & Department of Health Social Services, Division of Pioneer Homes
State Program
Average Annual Cost per Recipient

Source: Senior & Disabilities Services SAMS, Department of Health Social Services, Division of Pioneer, FY 2015 State Budget, April 2014 SDS Presentation.

Note: All costs include federal dollars that reimburse the state. Pioneer home costs include private pay.
Alaska’s Roadmap to Address Alzheimer’s Disease and Related Dementia (ADRD)

Why is the Roadmap important?

• This is the first ever statewide planning process for ADRD.
• Dementia creates severe hardship for both the individual and family.
• There is no known cure or prevention for Alzheimer’s disease.
• Alaska’s senior population is growing at a faster rate than any other state in the nation and advanced age is the #1 risk factor for developing ADRD.
• The Alaskan population of those with ADRD is projected to increase over 80% from approximately 8,000 people today to over 14,000 in 2025 (in just 10 years) and then continue growing rapidly through 2035.
• ADRD is a public health priority which will require the identification and implementation of best practices.
Roadmap Goals


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 care workforce trained in dementia care.

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

Seven Prioritized 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 (Strategy 1.1.1). Convener: Alzheimer’s Resource of Alaska

2. Assess feasibility and design an implementation plan for a potential 1915(i) and 1915(k) HCBS State Medicaid Plan amendments (Strategy 2.1.1). Convener: The Trust

3. Identify the DHSS resources needed through 2025 and 2035 to ensure those with ADRD can remain living safely at home or family caregiver’s home for as long as possible (Strategy 2.4.1). Convener: Senior & Disabilities Services.

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 (Strategy 3.2.1). Convener: Long-term Care Ombudsman

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, & mental health (Strategy 4.2.1). Convener: Pioneer Homes

6. Increase training to caregivers about ADRD, resources available and approaches/strategies for providing care and reducing stress and fatigue (Strategy 5.1.1). Convener: AARP Alaska

7. Increase in-home respite and adult day services to meet caregiver needs for appropriate breaks in providing care (Strategy 5.1.2). Convener: Alaska Commission on Aging
Goal 2.1.1
Medicaid Reform: 1915(i) and 1915(k) Options

Recommended Medicaid State Plan Amendments

• **Option 1915 (k) - “Community First Choice”**
  • Provides an opportunity to refinance Personal Care Assistant (PCA) services allowing the state to garner an additional 6% federal match.
  • Provides “cueing and supervision” specialized services for persons with dementia and other cognitive impairments.

• **Option 1915 (i)**
  • Provides a broad array of appropriate services for persons with dementia and other cognitive impairments who do not qualify under the current waiver.
  • Provides potential savings to the State’s General Relief Assistance program, Grant Programs, and Personal Care Assistance.
  • Provides a new funding source for the Pioneer Homes for residents with ADRD now covered by Payment Assistance.
  • Could serve persons at 300% SSI, the same income threshold as the 1915(c) waiver, if Alaska chooses this option.
  • Fills in the service gap of the (k) option.

• **WHAT’S NEXT....**

**Bottom Line:** The fiscal impacts are complex and need further study. Implementing the (k) and (i) options to the Medicaid State Plan show promise for Alaskans with cognitive impairments such as Alzheimer’s disease & related dementias.

*Source: Centers for Medicare & Medicaid*
Next Steps

The Roadmap is a *living document*. The Core Team is:

- Convening stakeholders around each strategy to develop the implementation plan which will include:
  - Specific action steps
  - Performance measures
  - Timelines
Thank You.

The Alaska Commission on Aging & the Alaska Mental Health Trust Authority