

Washington State Plan to Address Alzheimer's Disease and Other Dementias

Core Report and Appendix A
January 1, 2016



**Preparing Washington for the Impacts of
Alzheimer's Disease and Other Dementias**

GUIDING PRINCIPLES

The following principles were identified by the Alzheimer's Disease Working Group as critical to success - they are assumed and emphasized throughout the Washington State Plan to Address Alzheimer's Disease.

Alzheimer's Includes Other Dementias

Reference to Alzheimer's in this Plan is considered to also include other forms of dementia.

Public-Private Framework

This is not intended as a "state government-only" Plan, but rather a framework for what public-private partners in Washington can do collectively.

Build Upon Other Work

Build upon what's being done nationally (e.g., National Alzheimer's Plan, CDC Healthy Brain Initiative), and on what's working in Washington, other states & nations.

Person & Family Centered

Develop the Plan with the needs of people with AD, their care partners, family members, and guardians at the forefront; this includes sensitivity to cultural values and beliefs.

Life Course Approach

We are in this together, from before diagnosis through end-of-life care. This Plan recognizes that we can each do something to help individuals and the State address this disease holistically.



STATE OF WASHINGTON
Office of the Governor

Dear Washingtonians:

Alzheimer's is the 3rd leading age-adjusted cause of death in Washington State. While death rates for cancer, stroke and heart disease have declined, the death rate for Alzheimer's is on the rise – currently, more than 107,000 people in Washington have Alzheimer's or other dementias, and unfortunately, that number is expected to double in the next 25 years.

Every part of our state is touched by dementia, including Alzheimer's disease. The impact is being felt by individuals and families who bear the greatest emotional and financial responsibility, by our employers and economy, by health care systems striving to meet complex needs and by local communities and state resources.

Great challenges present great opportunities, and one of these opportunities can be seen in work that has grown out of the Aging Summit I convened in 2013. During that summit, great public and private leaders from across the state identified the need to produce an Alzheimer's and other dementias state plan. In 2014, the legislature took up that call to action and passed legislation for the development of a state plan.

As a result, we have formed a cross-sector Alzheimer's Disease and Dementia Working Group – made up of consumers and public-private stakeholders – to identify major goals, strategies and recommendations as part of our state plan. This is a starting point to prepare Washington State for meeting this challenge.

While there is still no known way to prevent or cure Alzheimer's, even though local researchers in our world-class bioresearch sector may be getting close to new effective treatments, our state plan proposes common sense steps that we can take to promote brain health; address legal, financial and care planning; improve the quality of life for those living with dementia; ease the strain on family caregivers and reduce associated costs in the future.

I commend the work to date and urge my administration, including leadership from the Department of Social and Health Services, Department of Health and Health Care Authority, to convene the next generation Alzheimer's Disease and Dementia Advisory Group and continue collaborating with the Group and stakeholders to move the recommendations forward.

Now is the time to take action that improves the health of people with, or at risk of, Alzheimer's or other dementias. Join us as we work together to that end.

Very truly yours,

Jay Inslee
Governor



Frequently Used Acronyms

AD	Alzheimer's disease and other dementias
APS	Adult Protective Services
AGO	Office of the Attorney General
ALTSA	Aging and Long-Term Support Administration of the Department of Social and Health Services
ADWG	Alzheimer's Disease Working Group
AAA	Area Agencies on Aging
CMS	Centers for Medicare and Medicaid Services
CDC	Centers for Disease Control and Prevention
DOH	Washington State Department of Health
DSHS	Washington State Department of Social and Health Services
HCA	Washington State Health Care Authority
HCS	Home and Community Services (part of ALTSA/DSHS)
LTSS	Long-Term Supports and Services
OPG	Office of Public Guardianship
RCS	Residential Care Services
UW	University of Washington

"The truth is that we simply must put Alzheimer's on the front burner because if we don't, Alzheimer's will not just devour our memories, it will also break our women, cripple our families, devastate our health care system and decimate the legacy of our generation. But if we do, I'm convinced that this Woman's Nation will be able to say that, believe it or not, there once was a time when there was no cure for Alzheimer's."

*Maria Shriver, author of The Shriver Report:
A Woman's Nation Takes on Alzheimer's*

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This report was prepared in response to SSB 6124 related to developing a State Alzheimer’s Plan. For additional materials used and prepared as part of this effort, visit the Alzheimer’s Disease Working Group’s website at:

www.dshs.wa.gov/altsa/stakeholders/alzheimers-state-plan

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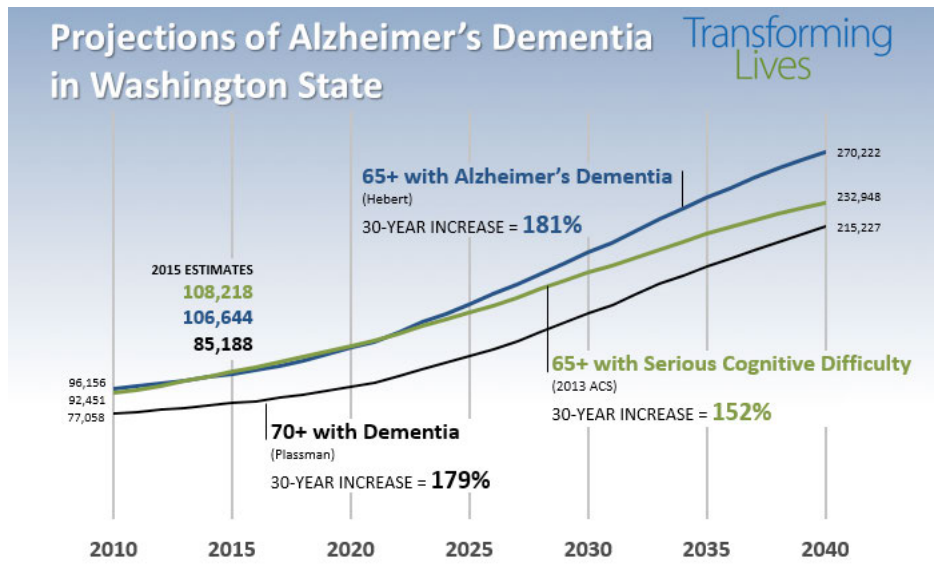
EXECUTIVE SUMMARY

THE IMPACT OF ALZHEIMER'S DISEASE IN WASHINGTON

Alzheimer's disease is the 3rd leading age-adjusted cause of death in Washington State. While death rates of cancer, stroke and heart disease have declined, the death rate for Alzheimer's is on the rise. Currently, about 107,000 people in Washington have Alzheimer's or other dementias. By 2040, that number is expected to grow to over 270,000.

Dementia, including Alzheimer's disease is one of the most costly chronic conditions to society. It poses a financial burden, similar to that of heart disease and cancer.

The progressive nature of dementia, its long duration, and its effects on memory, self-care, decision-making, and behavior create particular challenges for individuals and families.



Family members provide the majority of care. It's estimated that there are up to 324,000 unpaid family caregivers of persons living with dementia in Washington State. For many, the demands of caregiving lead to negative outcomes – stress, health risks, isolation, depression, and financial strain. Dementia also impacts Washington's employment and economy as more family caregivers need to miss work days, reduce work hours or leave their jobs.

Washington State's long-term services and supports system (LTSS) has demonstrated the ability to provide the majority of LTSS in the community. However, the system is already struggling to keep pace with the demand. The growing dementia population across the state will require us to intensify efforts to improve access to, and dementia-capability of, long-term services and supports.

Lack of early diagnosis leads to missed opportunities for: treatment; support and education for individuals and families; making legal and financial plans; and identifying choices for end-of-life care. It also contributes to otherwise preventable emergency room visits and hospitalizations. As health care system improvements such as Healthier Washington evolve in Washington State, it is essential that best practices around the early detection, diagnosis, treatment and management of dementia and co-occurring chronic illnesses are integrated into practice.

HOW WILL THIS PLAN HELP?

There is still no known way to prevent or cure Alzheimer's, but there are steps that individuals, the state and community partners can take to promote healthy aging and brain health, to improve the quality of life for those living with the disease, to ease the strain on family caregivers, and to reduce associated costs in the future.

During the Aging Summit, convened by Governor Jay Inslee in 2013, leaders from both public and private sectors identified the need to produce a state plan to address Alzheimer's disease. In 2014, the legislature took up that call and passed legislation to do so.

The Alzheimer's Disease Working Group (ADWG), appointed through Substitute Senate Bill (SSB) 6124, was charged with examining the needs of individuals with Alzheimer's, the services available to meet these needs, and the capacity of the state and current providers to meet these and future needs.

"I had to sell everything including jewelry, clothes and shoes. I wanted to keep us all together for as long as possible. Our high school son even handed over his college fund account. [My husband] forgot his children, he forgot his own home, and then he forgot me."

Debbie H., caregiver

While LTSS are an important (and the most costly) component of dementia care, the ADWG finds that dementia is a critical public health issue and recommends that the state adopt a

more comprehensive set of strategies to respond as future needs expand. This includes a change in thinking and practice in terms of medical care for individuals with dementia and closer coordination between medical care, LTSS and community services.



This plan shares findings of the ADWG on needs around the state, and offers forward-thinking strategies and actions to galvanize public and private stakeholders in preparing Washington State for the significant increases in Alzheimer's and other dementias that lie ahead.

A CALL TO ACTION

This plan is a starting point. It builds on opportunities to make positive changes, offering hope for living better with dementia by promoting early detection and better management of the condition, protecting persons with dementia from abuse and exploitation, expanding cost-effective services for people with dementia and their family caregivers, preparing communities for dementia, and improving the dementia-capability of long-term services and supports.

The ADWG believes the recommendations will have a positive impact for all stakeholders from individuals with dementia, to families, providers and governments; and issues a call to action:

- To establish a next generation Alzheimer's/Dementia Action Advisory Group to provide guidance and oversight to state plan implementation;
- To collectively pursue the goals, strategies and recommendations;
- To engage and sustain commitment from a network of public and private partners;
- To integrate activities into broader initiatives that are addressing improved health and quality of life such as Healthier Washington, the Medicaid Transformation Waiver, and the Bree Collaborative End of Life Care Recommendations;
- To identify opportunities to improve our state's response to dementia.

GOALS AND STRATEGIES

1 INCREASE PUBLIC AWARENESS, ENGAGEMENT AND EDUCATION

STRATEGIES

- A. Ensure statewide coordination of information and referral
- B. Create a sense of hope and empowerment for people with dementia and reduce stigma
- C. Promote early detection and diagnosis
- D. Promote advance care planning and legal and financial planning in the early stages of dementia in order to avoid costly or unnecessary court proceedings and/or guardianships
- E. Increase public awareness via educational and promotional campaigns developed and implemented collaboratively with the public and private sectors
- F. Increase public awareness about the connections between health and wellness, brain health, and dementia

2 PREPARE COMMUNITIES FOR SIGNIFICANT GROWTH IN THE DEMENTIA POPULATION

STRATEGIES

- A. Attain, analyze, and use available data
- B. Include Alzheimer's, dementia and healthy aging in state and local government plans
- C. Infuse age-friendly and dementia-friendly concepts into local communities
- D. Promote healthy aging and brain health

3

ENSURE WELL-BEING AND SAFETY OF PEOPLE LIVING WITH DEMENTIA AND THEIR FAMILY CAREGIVERS

STRATEGIES

- A. Increase awareness to reduce the risk for neglect, abuse, and exploitation of people with memory loss
- B. Promote in-home and community safety and the quick return of people with dementia who may wander
- C. Enhance legal protections for people living with dementia
- D. Promote practices to ensure driving safety of individuals with memory loss and/or dementia

4

ENSURE ACCESS TO COMPREHENSIVE SUPPORTS FOR FAMILY CAREGIVERS

STRATEGIES

- A. Provide guidance and support for dementia caregivers in navigating service systems
- B. Increase availability of, and access to, education and support services
- C. Increase availability of, and referral to, support groups for caregivers
- D. Increase access to respite
- E. Reach individuals and family members early in the disease process through collaborative models of social engagement
- F. Increase the number of culturally and linguistically-diverse caregivers who participate in education and support programs
- G. Collaborate with Tribes to meet unique needs of Native American family caregivers living with dementia
- H. Develop supports for family caregivers who are employed, caring for people with developmental disabilities and dementia, and those living with younger onset dementia
- I. Expand tele-health and web-based resources for family caregivers

5

IDENTIFY DEMENTIA EARLY AND PROVIDE DEMENTIA-CAPABLE EVIDENCE-BASED HEALTH CARE

STRATEGIES

- A. Endorse a set of evidence-based standards of care for dementia to promote high-quality health care
- B. Promote early detection, diagnosis and treatment
- C. Develop a dementia-capable, culturally competent primary care workforce throughout the state
- D. Support development and implementation of dementia-related, outcome-based performance measures
- E. Support policies that promote the capacity of primary care to adequately screen, diagnose, counsel, and treat patients with cognitive impairment/dementia

- F. Increase awareness of the challenges associated with dementia and co-occurring conditions
- G. Reduce preventable emergency department visits, hospitalizations and readmissions by improving communication and transitions of care
- H. Improve understanding of, and response to, challenging and/or complex behaviors
- I. Increase primary care workforce awareness of the critical role of care partners/caregivers

6

ENSURE DEMENTIA-CAPABLE LONG-TERM SERVICES AND SUPPORTS ARE AVAILABLE IN THE SETTING OF CHOICE

STRATEGIES

- A. Enhance coordination of care
- B. Expand access to affordable care to delay nursing home placement and spend-down to Medicaid
- C. Strengthen numbers and effectiveness of LTSS workers
- D. Reduce the burden of long-term care costs on families and the state
- E. Improve the quality of long-term services and supports for people with dementia
- F. Increase awareness of assistive technologies that promote independence for people with dementia and support for family caregivers

7

PROMOTE INNOVATION AND RESEARCH RELATED TO CAUSES OF AND EFFECTIVE INTERVENTIONS FOR DEMENTIA

STRATEGIES

- A. Increase support for basic, clinical and translational research around cognitive health, dementia and effective dementia care
- B. Develop relationships with key community stakeholders to assess and pilot culturally-specific/relevant services
- C. Increase the number of research participants

Specific problems, needs, recommended actions steps and timeframes for each strategy are included in the full report www.dshs.wa.gov/altsa/stakeholders/alzheimers-state-plan.

NEXT STEPS

The broad and complex nature of this Plan requires collaboration among many partners, and a phased approach to implementation with short-, mid- or long-term timeframes for each recommendation. The timeframes suggested are based on current resources and may be adjusted as staff and funding resources allow.

In early 2016, the Governor and partners have agreed to convene the next generation Alzheimer's Disease/Dementia Action Advisory Group to develop a work plan for implementation, determining when, and by whom, each short-term recommendation will be acted upon.

TRENDS AND SERVICE NEEDS OF ALZHEIMER'S POPULATION

Dementia is a general term used to describe a group of conditions characterized by the loss of memory and other cognitive abilities severe enough to interfere with daily life. This might include changes in language, problem-solving, or the ability to recognize or identify familiar people, places, or objects.

Alzheimer's disease is the most common form of dementia, accounting for 60-80% of cases, and vascular dementia is the next most common at around 17% of cases.¹ Other causes include: Lewy body dementia, mixed dementia, Parkinson's disease dementia, frontotemporal dementia, and Creutzfeldt-Jakob disease.



Different causes of dementia are associated with distinct brain changes and symptoms. More information is included in *Appendix C: Information about Alzheimer's and Dementia*

Throughout this report, use of the term "Alzheimer's Disease" is meant to be inclusive of Alzheimer's disease and other dementias.

The Alzheimer's Association identifies **ten early signs and symptoms of dementia**:

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

See Appendix C: Information about Alzheimer's and Dementia for more on the warning signs

RISK FACTORS FOR DEMENTIA

While the greatest risk factor is advancing age, many older adults who are in their nineties do not have Alzheimer's disease. And while family history and associated genetic influences are

important predictors, many family members of those with Alzheimer's will not develop the condition. This makes it important to identify and address other disease modifying factors.

Research is starting to reveal clues about risk factors that we may be able to alter through lifestyle, wellness, and managing other health conditions - such as head trauma, the heart-head connection, and healthy aging. Some healthy lifestyle and chronic disease management strategies are good for healthy aging and may prove, with further research, to directly protect against cognitive decline and Alzheimer's disease. For example, preventing falls to avoid head injury, physical activity, healthy diet, avoiding tobacco and excess alcohol, getting enough sleep, staying social, and managing heart disease, diabetes and blood pressure.

Leaders of the national Healthy Brain Initiative say that "Productivity, independence, and quality of life for millions of Americans depend on the nation's collective ability to prevent and treat cognitive impairment and dementia, and to promote cognitive functioning for individuals living in our communities. To accelerate efforts to meet these goals and help incorporate cognitive health in the plans and initiatives of states, territories, and communities in the U.S., we look forward to working with our partners to implement the actions identified in The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013–2018."²

"I would hope that efforts to address Alzheimer's disease in WA state will also be mindful of health disparities and recognize (and prioritize) the fact that certain racial, ethnic, and socioeconomic groups may be at greater risk for Alzheimer's, including women."

A family member in Washington

Productivity, independence, and quality of life for millions of Americans depend on the nation's collective ability to prevent and treat cognitive impairment and dementia, and to promote cognitive functioning for individuals living in our communities.

The Healthy Brain Initiative



THE CURRENT AND FUTURE IMPACT OF DEMENTIA IN WASHINGTON STATE

Every part of our state is touched by Alzheimer's and other dementias. The impact is already being felt across Washington State – on individuals and families who bear the greatest emotional and financial responsibility, on businesses through lost productivity of family caregivers, and on local communities and the State that incur significant costs for care and services. And, the greatest challenges are yet to come.

CURRENT STATE OF THE STATE

ESTIMATES OF PREVALENCE

While a precise number of people in Washington State with Alzheimer's disease and other dementias is unknown, there are different ways to estimate the prevalence. Three different approaches were used by DSHS' Research and Data Analysis Division to develop an estimate. One of the most commonly used approaches uses data from a study by Dr. Hebert et al. Using this approach, in 2015 the number of people living with dementia, including Alzheimer's disease in Washington State is estimated at 106,644.³

The first National Plan to Address Alzheimer's Disease, released in 2012, recognizes Alzheimer's disease as a major public health issue.

United States Department of Health and Human Services, 2012

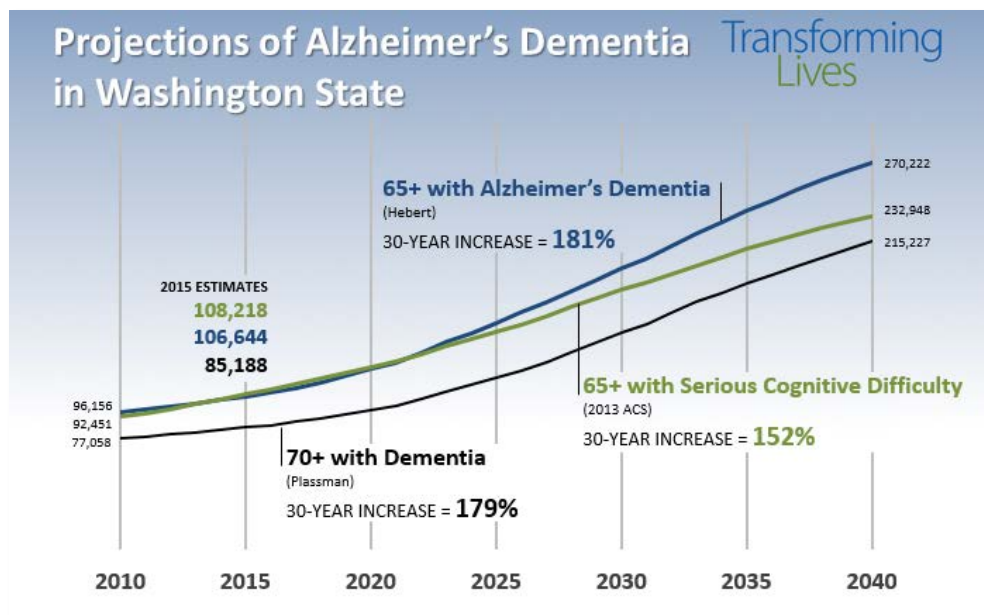


Figure 1. Projection of Alzheimer's disease in Washington State from three separate studies.

GROWTH OF THE “OLDEST-OLD”

While Alzheimer’s disease is not a normal part of aging, age is the greatest risk factor for developing Alzheimer’s or other dementia.⁴ Our longer lives increase the risk of developing dementia. People who are age 85 or older are defined as the “oldest old”, and are the fastest growing age group in the U.S. The risk of developing Alzheimer’s doubles every five years after age 65. While the prevalence of Alzheimer’s among people age 65-74 is 6.4%, it rises to over 30% among people 85 or older.⁵

In 2011, the first baby boomers started reaching 65 years of age.⁶ Washington State now has the 12th highest life expectancy nationwide.⁷ The combination of the increasing older population and the increased likelihood of dementia with advanced age will lead to the anticipated growth of the dementia population.

Unless the disease can be effectively treated or prevented, the number of Washingtonians with Alzheimer’s and other dementias will increase significantly in the next 25 years. Using prevalence projections and population estimates, we expect up to 270,000 citizens age 65 or older will have a form of dementia in 2040.^{8,9,10} This represents an increase of up to 181%, depending upon the prevalence estimates used.

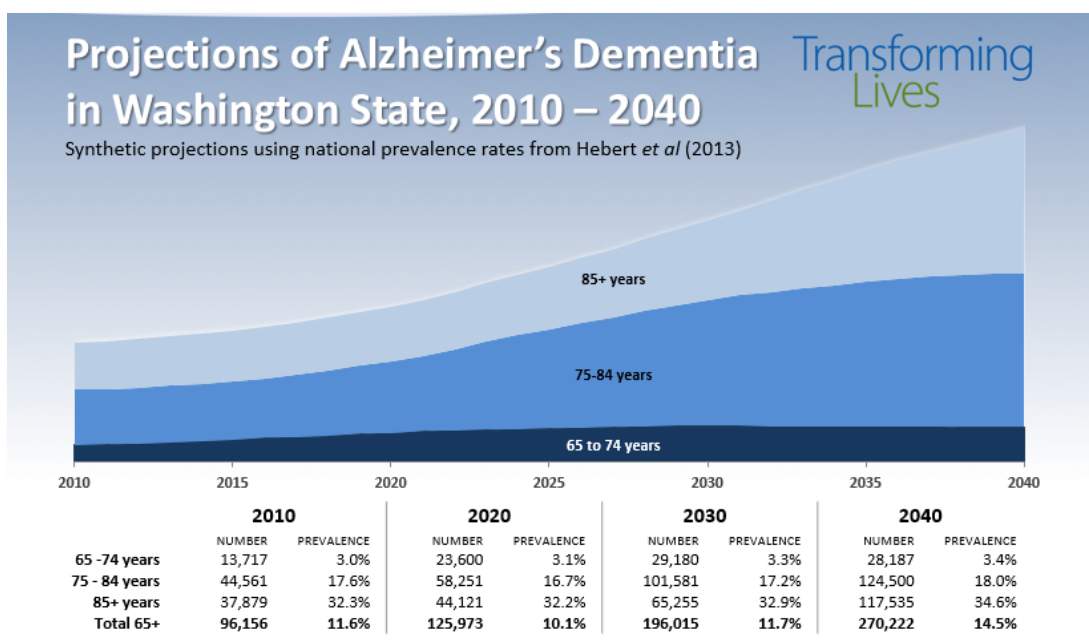


Figure 2. Projections of Alzheimer's disease in Washington State by age range, 2010-2040.

DEATH RATES FOR ALZHEIMER’S DISEASE

Alzheimer’s is now the 3rd leading age-adjusted cause of death in Washington State at 44.1 deaths per 100,000 people, age-adjusted to the U.S. 2000 population.¹¹ While death rates for cancer, stroke and heart disease have declined, the death rate for Alzheimer’s is on the rise. In

2014, 3,342 people died from Alzheimer's in Washington according to Department of Health vital statistics records.¹²

2005-2014 Percent Change in Death Rates in Washington State

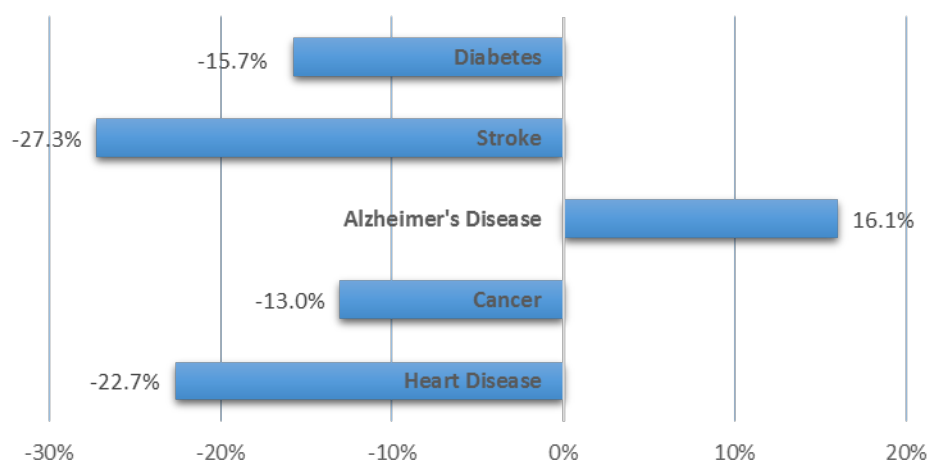


Figure 3. Percent change in death rates from 2005-2014, Center for Health Statistics, WA State Department of Health (2015).

An important confounding factor when comparing mortality rates from different diseases and in different populations is age. The process of age-adjustment removes the differences in age composition in two populations to allow comparisons of the two populations independent of their age structures. An age-adjusted death rate in Washington State is the weighted average of the age-specific death rates observed in Washington with the weights derived from an external population standard (in this case the year 2000 US census—this is the standard for health research). Using age-adjusted rates allows the comparison of the rate over time or the comparison of Washington with other states.

It is difficult to determine exactly how many deaths are caused by Alzheimer's each year because of the way causes of death are recorded on death certificates. It is likely that Alzheimer's is a contributing cause of death for more Americans than the data indicates. For example, an individual may be identified as having died of pneumonia, despite their diagnosis of Alzheimer's. The level of detail for collecting and analyzing death data can vary from state to state.

Washington State has the highest rate of death from Alzheimer's disease of any state. Washington's more rigorous approach to collecting and verifying detailed death data may contribute to the state's higher rates of Alzheimer's deaths compared to other states. When comparing rates of death from all forms of dementia (including Alzheimer's) to the U.S., Washington falls in the middle of all states.

IMPACT ON INDIVIDUALS

Studies suggest that people 65 and over live on average four to eight years after a diagnosis of Alzheimer's disease, but some survive as long as 20 years. The progressive nature of dementia, its long duration, and effects on decision-making, self-care and behavior create particular challenges for individuals.

In the early stages, declining memory may lead to challenges in managing work, finances or health care issues, including taking medications. As the disease progresses, people with dementia may also experience difficulty in initiating activities, decision-making and behavioral symptoms, such as depression and agitation.

Over time, they depend more and more on family or others to help them with daily living to remain at home or with a family member. More than 60% of people with dementia may wander away from home at some point in the disease. And falls are more frequent for people with dementia – and one of the most common reasons for hospitalization of people with Alzheimer's.¹³ Eventually, people with dementia need total help with bathing, dressing, eating and toileting.

Even so, a significant number of people with dementia live alone. While 42% of Medicare Beneficiaries, 65+ and diagnosed with Alzheimer's or other dementia, lived in a nursing home or other residential facility, the remainder lived in the community either alone or with another person. Of those living in the community, 25% lived alone.¹⁴ Another study estimated that among people 71 years and older, 17 percent of people with severe dementia and 25 percent of people with moderate dementia live alone.¹⁵

The symptoms of Alzheimer's and other dementias, such as impairments in memory, judgment, and the ability to plan and carry out activities, create greater risks for self-neglect, malnutrition, injury, medication errors, financial exploitation, unmet care needs, and nursing home placement – which is even greater for those who live alone.

Perceptions of Dementia

Americans fear Alzheimer's disease more than any other disease, including cancer.

(Marist Institute for Public Opinion, 2012)

About 75% of adults report not being knowledgeable about Alzheimer's disease.

(Anderson, Day, Beard, Reed, & Wu, 2009)

Falls and Dementia

Falls are more frequent for people with dementia – and one of the most common reasons for hospitalization of people with Alzheimer's

(Stark, et al., 2013)

Those with dementia who live alone and have no one who visits, helps, or checks in regularly are the most likely to fall through the cracks. Their unmet needs become clear only when they have a medical or other care-related crisis, and emergency response from health care, law enforcement, or Adult Protective Services (APS) agencies has been required.

During the later stages of the disease, a large percentage of people with dementia can no longer live at home. A person with Alzheimer's will spend 40% of the total number of years with Alzheimer's in the most severe stage of the illness.¹⁶

IMPACT ON FAMILIES

Dementia affects the whole family. Family members provide the vast majority of care for those living with dementia. Family members caring for a person with dementia in America, provide an average of 21.9 hours per week of care.¹⁷ It is estimated that there are currently between 286,000 and 324,000 unpaid family caregivers of persons living with dementia in Washington State.¹⁸

While most family members provide such care willingly and experience benefits through this role, for many the demands of caregiving lead to negative outcomes – stress, health risks, depression, and financial strain. Washington's Behavioral Risk Factor Surveillance System (BRFSS) findings reveal that the greatest impacts on dementia caregivers are increased stress, not enough time for self or family, and adverse impacts on family relationships.¹⁹ Findings also indicate that caregivers of people with dementia are twice as likely, as compared to caregivers of people without dementia, to experience a serious mental health condition such as depression and/or anxiety.²⁰ They are also more likely than non-caregiving peers to report their health as fair or poor.²¹

These emotional and physical impacts lead to increased health care costs for dementia caregivers nationwide. In Washington State alone, dementia caregiving contributes to about \$200 million of higher health care costs per year.²²

"Dementia in a family member can be a very divisive issue. For individuals who develop dementia, their care may be compromised if they don't have advanced medical directives or a power of attorney in place before symptoms develop. Conflict within families over the treatment of a family member with dementia is painful and can lead to great animosity, as it has within my own family. I hope further education on establishing a power of attorney/advanced medical directives and other long-term care issues is included in any plan regarding dementia."

A Washington caregiver

Dementia caregiving also impacts the ability to maintain an income: almost 40% of caregivers nationally reported either reducing their work hours or leaving their jobs to care for a family member with dementia.²³

The cost of caring for a person with dementia is daunting - the high costs of care pose real challenges and consequences for Washington families. In 2015, the median rate of assisted living facility care in Washington

State was \$55,500 and nursing home care \$96,933 per year. The costs for specialized dementia care in either of these settings is even higher. For home care, the median rate is around \$24 per hour.

In Washington State alone, dementia caregiving contributes to about \$200 million of higher health care costs per year.

(Alzheimer's Association, 2015)

While low income families can access Medicaid funded long-term supports and services, middle-

income families must pay for these services themselves – at least until assets are exhausted. In situations of younger-onset Alzheimer's disease, the loss of employment impacts income and health insurance as well. These families often have children still at home, compounding the impact.

The duration of dementia, and high costs of care commonly result in families depleting their resources and eventually turning to public programs for financial assistance. The aging of the baby boomers is expected to increase the proportion of middle-class families who will “spend down” their assets to Medicaid eligibility in the future.²⁴

IMPACT ON DIVERSE AND RURAL POPULATIONS

Available statistics indicate that in the U.S. older African-Americans are twice as likely as older whites to have Alzheimer's disease and other dementias.²⁵ Hispanic/Latinos are about 1.5 times as likely to have dementia.²⁶ There is limited data about the prevalence of Alzheimer's disease and other dementias in other racial and ethnic groups, including American Indian/Alaska Natives and Asian-Americans. Differences in language and culture create heightened barriers to education and support resources for these populations. For example, while undiagnosed Alzheimer's is an issue for all groups, Medicare data indicate that African-Americans are less likely than whites to be diagnosed. And when diagnosed, African-Americans and Hispanics are generally diagnosed in later stages of the illness – the impact of this is a higher use of health care services and higher costs.²⁷

Individuals with Down syndrome, due to a genetic link between the conditions, are also disproportionately impacted by Alzheimer's. If occurring, the onset of Alzheimer's may occur in this group in their 40s or 50s. When adults with Down syndrome are still living at home, parents who may be in their older years may still be in a caregiver role; other times this role may need to shift to other family members. These family members, or paid providers of care, need to be informed about changing expectations and care needs if Alzheimer's does occur, and the possible need for additional care support.

Washington's rural communities will also be significantly impacted. In 2030, about 19 counties, mostly in rural areas, will have about a third of their population age 65 or older. For example, in 2030 over 4 in 10 Wahkiakum County residents will be age 65 or older. Statewide, an estimated 17%, or 18,000 seniors, with Alzheimer's or dementia live in rural areas of Washington.²⁸ See *Appendix F: Prevalence and Forecasts of the Dementia Population* for county statistics and projected growth of aging population by county. In general, people living in rural areas have fewer financial resources, health and social services, public transportation options, and younger people living in their communities than do their urban or suburban peers.²⁹ Studies that look at the experience of dementia in rural communities show that there is generally a greater reliance on informal rather than formal support services.³⁰ This increased reliance on family and limited use and availability of services has impacts on the stress of these caregivers, on rural workplaces, and on the finances of families.³¹

"I live in [an area where] there is no public transportation, [and] feel rather alone, it's exhausting providing 24-hr care to a man who can do nothing, I have difficulty caring/lifting/transporting him.

Seeing an elder care attorney is expensive. Young Onset presents its own set of difficulties that a person set in retirement doesn't face. Young Onset takes many of your income earning years so the family is left to suffer. Now I have to spend his retirement on his care and I will be left on public assistance at some point. It's just so very hard."

A Washington caregiver



"If you don't live in the Seattle area or Vancouver, any services are not prolific. While I understand some programs are based on population, it feels as if folks have to rely on for-profit companies for community programs instead of non-profit or state agencies that have been developed for support of the elderly and disabled. Programs are too infrequent to be available when the need arises."

A family member from Washington

IMPACT ON GOVERNMENT AND OTHER PAYERS

Dementia, including Alzheimer's disease is one of the costliest diseases to society. It poses a financial burden, similar to that of heart disease and cancer. The largest component of costs attributable to dementia is the cost for institutional and home-based long-term supports and services.³²

The federal Medicare program covers costs for hospice care and a major portion of costs for short-stay, post-acute care in nursing homes for Medicare beneficiaries. Medicaid is a joint federal and state government program that helps people with low income and assets to pay for medical and long-term care. Medicaid plays an important role for people with dementia who cannot afford to pay for long-term care on their own. Medicaid covers nursing home care and home and community-based alternatives for those who meet financial and functional eligibility requirements. Medicaid is the largest single payer for formal LTSS.³³

The total per client Medicaid payments for Medicare beneficiaries age 65 and over with Alzheimer's and other dementias were 19 times as great as those for Medicare beneficiaries without the illness.³⁴

Table 1. Unpublished tabulations based on data from the Medicare Current Beneficiary Survey for 2008. Prepared under contract by Julie Bynum, M.D., M.P.H., Dartmouth Institute for Health Policy and Clinical Care, Dartmouth Medical School, November 2011.

Average Annual Per-Person Payments for Health Care and Long-Term Care Services, Medicare Beneficiaries Age 65 and Older, with and without Alzheimer’s Disease and Other Dementias and by Place of Residence, in 2014 Dollars

Payment Source	Beneficiaries with Alzheimer’s Disease and Other Dementias by Place of Residence			Beneficiaries without Alzheimer’s Disease and Other Dementias
	Overall	Community-Dwelling	Residential Facility	
Medicare	\$21,585	\$19,223	\$24,884	\$8,191
Medicaid	11,021	242	26,086	574
Uncompensated	297	427	117	335
HMO	1,083	1,681	247	1,579
Private Insurance	2,463	2,707	2,122	1,657
Other Payer	986	178	2,115	156
Out of Pocket	10,202	3,449	19,642	2,487
Total*	\$47,752	28,102	75,217	15,115

*Payments from sources do not equal total payments exactly due to the effect of population weighting. Payments for all beneficiaries with Alzheimer’s disease and other dementias include payments for community-dwelling and facility-dwelling beneficiaries.

Created from unpublished data from the Medicare Current Beneficiary Survey for 2008.

People with dementia, even with financial support, have high out-of-pocket costs. These costs include premiums and deductibles for Medicare, copayments, and services not covered by Medicare or Medicaid. The higher costs and out-of-pocket expenses for people with dementia contribute to a greater dependence on Medicaid. Twenty-nine percent of persons with Alzheimer’s or other dementias qualify for Medicaid compared to only 11% of those without Alzheimer’s or other dementias.³⁵

Washington State’s long-term supports and services system (LTSS) is ranked #2 in the nation by AARP. Washington State’s system has demonstrated the ability to provide the majority of LTSS in the community – delaying and avoiding nursing home placement by increasing availability of family caregiver supports, in-home services and residential LTSS options. However, the system is already struggling to keep pace with the demand. Increasing needs of the growing dementia population

Twenty-nine percent of persons with Alzheimer’s or other dementias qualify for Medicaid compared to only 11% of those without Alzheimer’s or other dementias.

(Alzheimer’s Association, 2015)

across the state will require that we intensify efforts to improve efficiencies as well as access to, and dementia-capability of, long-term supports and services.

IMPACT ON HEALTH CARE SYSTEMS

As the number of people with Alzheimer's and other dementias increases, so will their presence in health care systems. The dementia population has more than triple the number of hospital stays per year as other older people.³⁶ People with dementia living in the community are more likely than those without dementia to have potentially avoidable emergency department visits or preventable hospitalizations.³⁷

People with Alzheimer's and other dementias are more likely to have other chronic conditions than those without the condition.³⁸ Studies of Medicare data show that people with dementia have more potentially avoidable hospitalizations due to complications of diabetes and hypertension – conditions that could be prevented through active care management.³⁹

The U.S. Department of Health and Human Services has targeted this concern in its Healthy People 2020 initiative – setting a target to reduce preventable hospitalizations for people with Alzheimer's disease and other dementias by 10% by 2020.⁴⁰

People with dementia have more potentially avoidable hospitalizations due to complications of diabetes and hypertension – conditions that could be prevented through active care management.

(Alzheimer's Association, 2015)

IMPACT ON BUSINESSES

Washington's businesses are also feeling the impact because of lost productivity as more and more employed family caregivers miss work days, reduce work hours or leave their jobs.

Research indicates that Alzheimer's and other dementias cost businesses nationwide \$61 billion a year. Around \$24.6 billion of this amount is directly related to costs associated with dementia such as health care, long-term care and hospice. Another \$36.5 billion is due to factors such as lost productivity. In a study of dementia caregivers who were employed at any time since becoming caregivers, 54% had to go in late or leave early and 15% took a leave of absence. Seventeen percent had to give up their jobs before or after assuming these responsibilities.⁴¹

THE STATE'S ROLE IN SERVICES FOR PERSONS WITH DEMENTIA AND THEIR CAREGIVERS

The legislation authorizing the development of this state plan called for the Alzheimer Disease Working Group (ADWG) to examine the array of needs of individuals diagnosed with Alzheimer's, along with the services available to meet these needs, and the capacity of the state and current providers to meet these and future needs.

This plan recognizes that much of the state's response to Alzheimer's disease up until this point has focused on development of the community-based long-term supports and services (LTSS) system, but that gaps in LTSS for persons with Alzheimer's and their caregivers do exist and will continue to grow. While community based long-term supports are a critical (and the most costly) component of dementia care, the ADWG believes that the state must adopt a much more comprehensive set of strategies to respond to dementia as future needs expand. This includes a change in thinking in terms of medical care for dementia and closer coordination between medical care, LTSS and community services.

The state plays a major role in the administration and provision of long-term supports and services for individuals with chronic illnesses or conditions and disabilities, including those with Alzheimer's disease and other dementias of all stages, and their caregivers.

Washington has a long and strong history of providing an array of long-term services and supports that allow individuals to choose among settings and providers that will best meet their needs. This has been accomplished through strong federal and state partnerships to leverage federal funding from the Administration on Aging which funds the Older Americans Act and many of the grants used over the years to test models of care, and with the Center for Medicare and Medicaid Services. These federal fund sources establish target populations, eligibility and services that Washington State knits together to create a system of care that is responsive and evolving.

The roles of the state are listed below by each agency, including special mention of any Alzheimer's or dementia-specific service or programs.

DEPARTMENT OF SOCIAL AND HEALTH SERVICES, AGING AND LONG-TERM SUPPORT ADMINISTRATION (DSHS/AL TSA)

Unlike many states, Aging and Long-Term Support Administration brings together under one administrative organization the Medicaid, federal Older Americans Act, as well as state funded services and supports for adults with physical and cognitive disabilities and their caregivers.

This includes Area Agencies on Aging providing in-home case management, Community Living Connections, family caregiver support, and other community-based resources; a statewide network of access points for Medicaid program/financial eligibility determination and case management services; statewide residential licensing, oversight and quality assurance

programs; Adult Protective Services, the state Office of Deaf and Hard of Hearing, and consolidated management functions.

ALTSA has two primary divisions that support the provision of long-term support services, including those for people with possible or diagnosed dementia – Home and Community Services and Residential Care Services.

HOME AND COMMUNITY SERVICES

Home and Community Services (HCS) provides and administers Medicaid funded **long-term care services (LTSS)** to eligible individuals and oversees contracts with **Area Agencies on Aging** to design and implement community based service networks.

HCS staff conduct assessment and eligibility determination for Medicaid long-term services and supports (LTSS) that are provided in the home, in licensed community residential settings such as Adult Family Homes (AFHs) and Assisted Living Facilities (ALFs) or in nursing homes. To do this, HCS coordinates and contracts with a network of providers to provide LTSS including in-home personal care, private duty nursing, adult day services, adult family homes, assisted living facilities, skilled nursing facilities, and other services designed to help individuals live in their own homes and communities.

HCS investigates reports of abuse, neglect, self-neglect, and exploitation of vulnerable adults. Through investigation, ALTSA provides protective services, refers individuals to Medicaid and community supports and maintains an abuse registry of individuals who have been substantiated to have committed abuse, neglect or exploitation.

HCS has also developed several programs and services to improve the quality of LTSS for people with dementia and to assist their family caregivers. These include the Specialized Dementia Care Program in Assisted Living Facilities, Dementia Specialty Training, and the Tailored Caregiver and Referral® (TCARE®) system available statewide through the Family Caregiver Support Program. An evidence-informed dementia day service model called Memory Care & Wellness Services, developed through federal demonstration programs and operating in three public service areas, as well as two evidence-based interventions - STAR-C dementia consultation and Reducing Disability in Alzheimer's Disease (RDAD) - are currently being implemented or translated in limited service areas. See *Appendix E: Inventory of Services* for more detailed information.

Currently, a federal Dementia Capable Systems grant (2014-2017) is piloting approaches to improve the capacity of front-line staff to recognize and respond with timely specialized information and referral for people with possible or early stage dementia.

Community services funded through the federal Older Americans Act and state funding are operationalized through thirteen Area Agencies on Aging, and discussed below.

AREA AGENCIES ON AGING

Area Agencies on Aging (AAAs) play a critical function in Washington State. They are a network of agencies charged by the Older Americans Act (OAA) as planning and service areas for issues related to older adults, defined as ages 60 and older. AAAs provide a comprehensive and coordinated local approach to managing a home and community system of services that are client centered, allow maximum flexibility and promote the efficient use of resources; emphasizing the least restrictive interventions and building on the individual's and their family's strengths and responsibility.

There are 13 AAAs in Washington State, all are part of local, county or tribal government structures. They provide services such as:

Community Living Connections – helping older adults, their family or other informal caregivers and professionals to plan for and find care and services in their local area; providing coaching in how to use their own resources, such as insurance and savings as well as access assistance through state and federal programs.

Family Caregiver Support Program – providing specialized information and assistance, respite care, counseling, consultation, support groups, education, and training to help unpaid family caregivers of individuals ages 18 years and older.

Federal Older Americans Act (OAA) and State Senior Citizens Services Act (SCSA) – providing nutrition/meals, health promotion, foot care, transportation, adult day services, personal care, and legal assistance for individuals 60 years of age and older.

Ongoing case management for individuals ages 18 and older who receive in-home services through Medicaid funded in-home personal care.

The state Family Caregiver Support Program is required to include services appropriate to the needs of “persons caring for individuals with dementing illnesses”, and serves informal caregivers providing care to individuals *of any age* with Alzheimer’s or other dementias, as does the national Family Caregiver Support Program. However, other services funded by the OAA serve individuals age 60 and over.

More information about the programs described above can be found in *Appendix E: Inventory of Services*.

RESIDENTIAL CARE SERVICES

Residential Care Services (RCS) is a division within the Aging and Long-Term Support Administration which falls under the Department of Social & Health Services. RCS’s role is to promote and protect the rights, security, and well-being of individuals living in licensed or certified residential settings within the State of Washington.

RCS licenses, certifies and provides regulatory oversight to assist providers with following the laws and rules that govern each of these settings:

- Nursing Facilities
- Assisted Living Facilities
- Adult Family Homes
- Intermediate Care Facilities for Individuals with Intellectual Disabilities
- Certified Residential Services and Support Programs
- Enhanced Services Facilities

These settings are inspected on a regular basis to ensure they meet the minimum care and safety requirements specified in law and rule. These compliance surveys and inspections are one of numerous quality assurance activities that occur within the licensed or certified homes/facilities.

RCS also has complaint investigators who investigate complaints in the licensed or certified homes/facilities related to provider practice and services concerns. These complaints are referred to RCS investigators by the DSHS Complaint Resolution Unit (CRU).

The CRU receives and prioritizes complaints regarding provider practice, including suspected abuse or neglect in long-term care settings that have been called into the CRU Hotline (1-800-562-6078). The CRU hotline is available 24 hours a day, seven days a week, for the public and licensed or certified homes/facilities staff. Licensed or certified homes/facilities staff are mandated reporters and are required to report specific types of incidence to the CRU hotline. Depending on the nature and severity of the reported issues, calls may also be referred to local law enforcement, licensing boards, Medicaid Fraud, county prosecutors and sheriffs, and Adult Protective Services.

The federal Centers for Medicare and Medicaid Services (CMS) has instituted new protocols to ensure surveyors/investigators are ensuring dementia care is reviewed. CMS has added dementia language to the federal regulation of Quality of Care allowing the surveyor/investigator the ability to issue a citation to a skilled nursing facility if they fail some part of dementia care for a resident.

DEPARTMENT OF HEALTH (DOH)

The Washington State Department of Health (DOH) works to protect and improve the health of all people in Washington State. This goal is achieved by protecting the population from communicable diseases and other health threats, preventing illness and injury, promoting ongoing wellness, and improving access to quality, affordable and integrated health care.

DOH and local health jurisdictions work collaboratively with many health partners including hospitals and clinics, the **University of Washington School of Public Health**, and state and local

community-based organizations, associations and coalitions. It also has close working relationships with federal agencies including the **Centers for Disease Control and Prevention**.

Current roles related to serving adults with cognitive impairment and/or dementia include:

- Licenses and regulates hospitals, home health and home care agencies, hospice agencies, and hospice care centers
- Provides quality assurance through regular surveying of all licensed health care facilities
- Provides quality assurance and quality information for consumers related to the agencies and facilities that DOH licenses and regulates
- Licenses health care providers including home care workers
- Responds to complaints against licensed providers and facilities
- Implements programs to decrease injuries, including falls
- Posts information on the DOH web site about advanced care planning
- Supports primary care providers and practice teams to develop and strengthen patient-centered medical homes, manage care for patients with multiple chronic conditions and improve care transitions
- Offers a free online training curriculum for community health workers that strengthens common skills, knowledge and abilities

HEALTH CARE AUTHORITY (HCA)

The Washington State Health Care Authority (HCA) is the state's Medicaid agency. HCA is Washington's largest health care purchaser, responsible for providing comprehensive health coverage to more than 2 million residents through the Public Employees Benefits and Medicaid programs. The agency provides health purchasing leadership, benefiting both public and private sectors, with a focus on moving the health delivery system toward higher value and better outcomes. HCA supports quality care and evidence-based medicine through programs such as the **Health Technology Assessment Program** and participation in the **Dr. Robert Bree Collaborative** (see next page). Current programs administered include:

Apple Health (Medicaid) – Medicaid provides health coverage to many Washingtonians, including eligible low-income adults, children, pregnant women, elderly adults and people with

“Behaviors related to dementia seem to still be vastly misunderstood. In my mind the emphasis with training and awareness campaigns needs to be in helping the caregivers, health practitioners, and collateral contacts (EMS, case managers, etc.) to learn the unique methods that can help a person with dementia or Alzheimer's to have less anxiety...”

A Washington caregiver

disabilities. The program is funded jointly by the state and the federal government. Coverage is free for those who qualify.

Public Employees Benefits Board (PEBB) – PEBB provides insurance coverage for eligible employees and retirees of state agencies and higher education institutions, certain employer groups, and their families. PEBB also supports public employee wellness through the Washington Wellness program.

Healthier Washington – Healthier Washington is Governor Inslee’s vision for creating healthier communities and a more sustainable health care system. Healthier Washington includes the following initiatives: the State Health Care Innovation Plan, Integrated Physical and Behavioral Health Purchasing, and the Medicaid Transformation Waiver.

Dr. Robert Bree Collaborative End of Life Care Recommendations

The Dr. Robert Bree Collaborative provides a forum in which public and private health care stakeholders can work together to improve quality, health outcomes, and cost-effectiveness of care in Washington State. End-of-life care was identified by the Bree Collaborative as an area with high variation and poor patient outcomes and the Bree Collaborative elected to form a workgroup. In 2014, the End-of-Life Care workgroup issued its report and recommendations, which can be found at www.breecollaborative.org/topic-areas/eol.

The goal of the Bree Collaborative is that all Washingtonians are informed about their end-of-life options, communicate their preferences in actionable terms, and receive end-of-life care that is aligned with their and their family members’ goals and values. The report includes five focus areas – all of which are important for people with dementia:

- 1. Increase awareness of advance care planning, advance directives, and POLST in Washington State.*
 - 2. Increase the number of patients who participate in advance care planning in the clinical and community settings.*
 - 3. Increase the number of patients who record their wishes and goals for end-of-life care using documents that: accurately represent their values; are easily understandable by patients, family members, and health care providers; and can be acted upon in the health care setting.*
 - 4. Increase the accessibility of completed advance directives and POLST for health systems and providers.*
 - 5. Increase the likelihood that a patient’s end-of-life care choices are honored.*
-

STATE POLICY REGARDING PERSONS WITH DEMENTIA, INCLUDING ALZHEIMER'S DISEASE

The state currently has limited policy language on Alzheimer's disease in legislation, relating to required training on dementia for adult family homes and assisted living facilities. Washington Administrative Code (WAC) addresses requirements for assisted living facilities to obtain specific information for a resident who has symptoms consistent with dementia including resident's significant life experiences, resident's patterns of behavior, and requirements related to restricted egress. In addition, there are physical facility requirements for Nursing Home Dementia Care Units.

The state – through its Department of Social and Health Services, Department of Health and Health Care Authority – support the principles of independence, healthy aging, preparing communities, offering choice and options for services and tailoring services to meet individual needs and preferences. Washington State has a number of policy directions for aging and long-term supports and services that promote community-based alternatives to nursing home care, support unpaid family caregivers, train the long-term care workforce, help people age in place, encourage active chronic care management, and promote the use of evidence-informed and evidence-based models for older adult services. These principles and policies apply to all older persons with or without dementia.

Impact of Dementia

Dementia presents distinct challenges for long-term supports and services systems (LTSS) because of “its high prevalence, progressive nature, effects on behavior and ability to self-manage care due to impaired cognitive and decision-making capabilities, frequency of care transitions, risk of elder abuse, high rate of comorbid health conditions, heavy reliance and resulting health impacts on caregivers, and higher costs associated with LTSS compared to other chronic conditions in late life”.

(Shih, et al, 2014)

The working group recognizes with this plan that Washington State needs a stronger statement on dementia as a critical public health issue, articulating the state's commitment to policies and actions that support its citizens at risk of and affected by the disease, and that prepares the state for the significant increases in Alzheimer's that lie ahead. If enacted, the proposed actions would demonstrate the state's commitment to prepare for Alzheimer's.

THE IMPORTANCE OF INTEGRATING ALZHEIMER'S/DEMENTIA IN HEALTH CARE REFORM

Washington State is currently engaged in the development and implementation of state level health care reform. Washington is focused on changes in the health system, that include a strengthened patient-centered medical home model concentrating on the concept of chronic care management, and implementation of Healthier Washington.

The Department of Social and Health Services, the Department of Health, and Health Care Authority each recognize the importance of addressing chronic conditions. DSHS' Aging and Long-Term Support Administration has been most engaged with dementia as a special focus due to the high need for health and long-term care services by persons with Alzheimer's and their caregivers.

"Seems primary care practitioners are dismissive when expressing concerns about changes in older family members with who you live and see on a daily basis."

A Washington caregiver

As health care system improvements evolve in Washington State, it is critical that emerging data and best practices around the identification, treatment and management of dementia and co-occurring chronic illnesses are integrated into systems improvements and transformation efforts at the state and local levels. Improvements must include the capacity to:

- Detect early signs and symptoms of cognitive impairment;
- Make and disclose a timely diagnosis;
- Promote advance planning for substitute decision-making and end-of-life care;
- Coordinate care for wellness, medical and support service needs;
- Provide early and ongoing education and support of family caregivers; and
- Promote independent and active engagement of persons with dementia in the community.



NEEDED POLICIES AND RESPONSES

PLAN DEVELOPMENT PROCESS

SSB 6124 authorized the creation of an Alzheimer's Disease Working Group (ADWG) to examine the needs of individuals with Alzheimer's disease, the services available to meet these needs, and the capacity of the state and providers to meet current and future challenges. The working group was also to make recommendations on needed policies and responses. The charge to the working group and full excerpt from the enabling legislation is included in *Appendix B: Legislative Charge*.

The legislation required that the group include representatives with a broad spectrum of knowledge, expertise and experience related to Alzheimer's disease. This group was fortunate to have the participation of six consumer representatives, two individuals with Alzheimer's and four family caregivers. A significant number of professional representatives also had personal connections with dementia. A full list of ADWG members, subject matter experts and staff included in this process, is included in the *Acknowledgements* section.

The ADWG members divided themselves into four topic-focused subcommittees to complete its charge. Each subcommittee focused on the issues within their particular topic area to identify key issues and priority needs, and develop recommendations to present to the full ADWG. The subcommittees created were:

1. Public Awareness, Outreach, Education
2. Public Health-Community Readiness
3. Health and Medical Care
4. Long-Term Supports and Services

A Planning Team, composed of leaders from the Governor's Office, Aging and Long-Term Support Administration (AL TSA), Alzheimer's Association, ElderCare Alliance and subcommittee chairs provided oversight and direction to the process. AL TSA engaged a professional facilitator and provided program management and subcommittee staff support. The Alzheimer's Association also contributed staff support to the process.

A [web page](#) was created for the work of the ADWG to share resources and reports from the National Alzheimer's Plan and other state's Alzheimer's plans, and to house information from ADWG meetings. This offered a place not only for ADWG members but for the public and interested stakeholders to be informed of the ADWG's efforts.

The process invited public participation and comment in several ways. Early in the process, two online surveys were conducted to seek input on priority issues related to dementia in Washington State – one targeted the general public, the other primary care practitioners. Mid-way through the process, seven community meetings were offered to solicit public input and specific suggestions related to questions posed by the ADWG. One of these sessions was with

the DSHS Indian Policy Advisory Committee (IPAC) subcommittee on Aging, one included a Spanish-language translator, and one was offered in the evening in webinar format. During the process, the public was invited to offer comment during the ADWG meetings. And, the draft plan was posted for public comment.

Over the past year, the ADWG used public input and expertise to identify high-level goals, strategies and recommendations. Each subcommittee presented their findings and priorities to the full ADWG at various points in the process – in January, May and July 2015.

What became clear out of these deliberations is that we need to change the way we think about dementia. It is paramount that we:

- Change beliefs about the importance of early detection and diagnosis among the public and health providers – from one where there is no reason to get a diagnosis because “there is nothing that can be done” to the view that there are valid benefits of an accurate, timely diagnosis.
- Change the stigma attached to dementia - from feelings of fear and disengagement to those of acceptance, hope and empowerment.
- Stimulate steps toward advance planning so that legal documents are in place and preferences are documented.
- Change the isolation experienced by caregivers to a greater sense of connection with others – and a recognition that there is help available.

“I encourage us as much as possible to use hope-filled rather than fear-based messaging, and to avoid sensationalized language that is often used in dementia-specific fundraising campaigns.

In our language and approach we have the opportunity to highlight persons living with dementia as vital members of our community, not as 'economic or caregiving burdens.'”

A social worker in Seattle



- Acknowledge that while there are no known cures or treatments for Alzheimer’s, there is emerging evidence that healthy living, including regular physical activity and attention to heart health, may also benefit cognitive or “brain health”.

The figure below depicts a model for viewing Alzheimer’s from both the life-course perspective and a coordinated systems approach. It is critical moving forward to recognize the opportunities to make impacts at each stage and to coordinate among care systems to improve outcomes for people with dementia and their family caregivers.

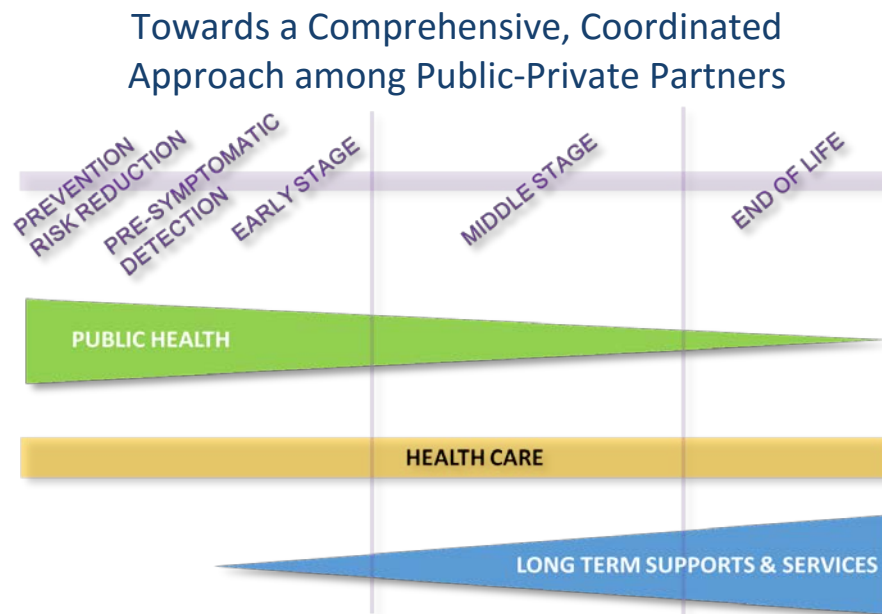


Figure 4. Model of a comprehensive, coordinated system to address dementia through the life cycle.⁴²

This model is in line with the view of the RAND “policy blueprint” for improving life-long care for people with dementia. In this document, RAND identified high-impact policy options that align with different stages of dementia. For example, policy options that are most relevant in the early stages of dementia are related to early diagnosis, assisting people with dementia and their caregivers with future planning, providing dementia-specific education and training for families and providers of care, and increasing access to community based services. Throughout all stages, the high-impact policy options focus on quality of care and minimizing transitions in care settings. In the later stages, policy options would include access to hospice care.⁴³

This plan does not propose to take on all aspects of dementia. **The intent was to identify the greatest needs and strategies at this point to begin preparing Washington State for the future.** Throughout its deliberations, the ADWG found agreement among its members on several key problems in the current care and support for persons with Alzheimer’s.

At the heart of the group’s vision for the future is changing how we approach and manage medical care for persons with cognitive impairment, and the critical need to promote the early detection, diagnosis and management of Alzheimer’s and other dementias. Early detection and diagnosis creates opportunities for better disease management and management of co-

occurring conditions, and allows the person and family to make plans for the future. Better disease management will also improve the quality of life and care over the course of the illness – whether the person is living at home or in a long-term care setting.

This vision includes critical support for the person with dementia and family shortly after diagnosis. Family caregivers need a “road map” offering simplified information about what to expect as the disease progresses and where to turn for help at any stage. Families also need to know that others providing for their family members are doing so within accepted standards of practice.

Our communities – local government, businesses, churches, health care, and social service organizations – also need to be better prepared for the growing number of citizens who will be affected by Alzheimer’s or other dementias. Community organizations need help providing education about healthy aging and maintaining a healthy brain, the importance of early detection and diagnosis, and where to turn for assistance. Together, we need to create more “dementia-friendly” communities that promote engagement, well-being, and safety.

Families are and will remain the bedrock of support and long-term care for people with Alzheimer’s. The intent of the ADWG is that the concept of family be liberally construed. In this state and in this plan, families are broadly defined and inclusive. When the term family is used in this document, it means each individual’s interpretation of who their kin are. Our rich state heritage provides countless examples of families, including large extended clans, long-term companions, same-sex and different-sex couples whether married or not, and relationships between people with a common history, emotional bond and commitment to an individual’s well-being. Essentially, family means any person who plays a significant role in an individual’s life.



“Help with access to secured and unsecured facilities, rates are too high and people are not accepted when on Medicaid.”

A family member in Washington

“Dementia-Capable” States and Communities

1. Educate the public about brain health. This would include information about the risk factors associated with developing dementia, first signs of cognitive problems, management of symptoms if individuals have dementia, support programs, and opportunities to participate in research.
2. Identify people with possible dementia and recommend that they see a physician for a timely, accurate diagnosis and to rule out reversible causes of dementia or conditions that resemble it.
3. Ensure that program eligibility and resource allocation take into account the impact of cognitive disabilities.
4. Ensure that staff communicate effectively with people with dementia and their caregivers and provide services that: (a) Are person- and family-centered; (b) Offer self-direction of services; and (c) Are culturally appropriate.
5. Educate workers to identify possible dementia, and understand the symptoms of dementia and appropriate services.
6. Implement quality assurance systems that measure how effectively providers serve people with dementia and their caregivers.
7. Encourage development of dementia-friendly communities, which include key parts of dementia-capability.

Dementia-Capable States and Communities: The Basics
U.S. Administration for Community Living, Administration on Aging, September 2014



WASHINGTON STATE'S SEVEN GOALS

The ADWG identified seven top-level goals to address Alzheimer's in Washington State. Each goal has 3-6 supporting strategies, and each strategy has 3-7 specific recommendations. The top-level goals are shown below.



GOALS, STRATEGIES, RECOMMENDATIONS AND PROPOSED POLICIES

The ADWG used a three-level approach to defining the recommendations. The goals are broad visionary statements. Underneath the goals, there are multiple strategies, or high-level plans to achieve the goals. Each strategy has one or more recommendations (responses or actions).

In recognition of the broad and complex nature of this Plan and the need to collaborate among many partners, the ADWG is suggesting a phased approach to implementation. The working group has identified suggested timeframes to initiate work for each recommendation. Short-term would be within 2 years, mid-term within 3-4 years, and long-term in 5 years or beyond. The identified timeframes are estimates. It is possible that there may be instances where some work may need to be deferred depending upon the availability of staff and budget resources. Conversely, preliminary work might start earlier on some recommendations. See *Implementation of the Alzheimer's Plan* for more information.

The Goals, Strategies and Recommendations of the ADWG are shown below. The columns on the right show suggested timeframes to begin work on each recommendation.

At the heart of the group's vision for the future is changing how we approach and manage medical care for persons with cognitive impairment, and the critical need to promote the early detection, diagnosis and management of Alzheimer's and other dementias.

Alzheimer's Disease Working Group

GOAL 1: INCREASE PUBLIC AWARENESS, ENGAGEMENT AND EDUCATION

Almost everyone is affected in some way by Alzheimer’s and other dementias, but many are unaware of where to go or what to do to get a diagnosis, obtain services and supports, or what help is available to a person with dementia and their family. Information about Alzheimer’s is sometimes difficult to find, and no comprehensive single source of information exists for Washington residents.

About half our survey respondents from across the state reported difficulty in obtaining a medical diagnosis. Only 14% received information about community resources from their provider once they were diagnosed. In our listening sessions held around the state, a large number of people shared how lost they felt after diagnosis, not knowing where to turn.

Information about dementia and resources for those who have been diagnosed and their care partners is not getting to them soon enough. It was noted frequently that health care providers are a trusted resource, but as they are sometimes not aware of what’s available in the community, they cannot share community resources with their patients.

“Get physicians, nurse practitioners, primary care providers up to speed about dementia and [the] resources available for patients and caregivers.”

A family member in Washington



Families also reported the impacts that lingering stigma places on them. Along with stigma, there can be a loss of hope and a sense that nothing can be done to change the inevitable outcome. Sometimes, people delay obtaining a diagnosis or identifying potential supports early because of this loss of hope. This in turn may prevent needed planning for the future. People with dementia report that many of their friends and neighbors drift away, leaving them socially isolated and alone.

"I would like to see the Alzheimer's groups become more proactive to reduce the number of persons with dementia who are placed under guardianships..."

Good planning can help individuals with dementia retain their rights and their dignity, as well as their life savings. Spouses of those with Alzheimer's disease should know what can be done to protect the well spouse from the costs of long-term care."

A family member in Washington

This plan was created with participation from people with Alzheimer's and family caregivers, to help ensure a person-centered focus and a collaborative "nothing about us without us" approach to identifying the following strategies and recommendations. We recognize the need to advocate for a person-centered approach when providing support for a person with Alzheimer's or their family. In addition to educating the general public, other professionals like judges, guardians, agency staff, and policy makers will need ongoing education regarding a person-centered focus and on the value of supported decision-making strategies which assists the individual in developing a person-centered plan and recruiting a team to assist with its implementation.

Dementia affects people of all races, ethnicities, income levels, gender identities, and sexual orientations. Military veterans who experience post-traumatic stress disorder or traumatic brain

injury may have a higher risk of developing dementia later in life.^{44,45} Some populations may experience additional health disparities, economic barriers, and challenges to accessing health care and supportive services. The first goal is about a culturally inclusive awareness and outreach plan that intends to increase consumer demand for early detection and diagnosis in order to improve the quality of life for persons with dementia. It considers a spectrum of people with dementia from younger adults to the end of life, those who don't speak English as their primary language; and it extends from urban to rural areas of Washington State. Goal one proposes to make bite-size pieces of information about best practices available to *all* Washingtonians.

Collaboration among many stakeholder groups is key to improving public awareness, especially utilizing organizations and groups that people trust to help convey important messages.

GOAL 1: INCREASE PUBLIC AWARENESS, ENGAGEMENT AND EDUCATION

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
A. Ensure statewide coordination of information and referral.	1. Establish a work group to develop, launch and oversee a single web-based “point-of-access” portal/website linking to a comprehensive statewide array of credible and validated information, resources and supports.	☑		
	2. Strengthen capacity of the Washington State Information & Assistance system by educating staff about recognizing possible dementia, making appropriate referrals by building links between relevant organizations.	☑		
	3. Offer materials and information to underserved populations, including rural populations; assure material on dementia is multi-cultural, multi-lingual, appropriate for persons with sensory limits (e.g., vision and hearing loss), and tailored to state demographics.	☑		
B. Create a sense of hope and empowerment for people with dementia and reduce stigma.	1. Promote positive images and messages of persons with dementia and their caregivers to combat stigma and increase societal acceptance and integration.	☑		
	2. Promote models of stigma-free, dementia-friendly communities, places and events (e.g., Alzheimer’s Cafes) to combat stigma and increase societal acceptance and integration.			☑
C. Promote early detection and diagnosis.	1. Educate the public about the importance and advantages of getting an early diagnosis and what to ask their health provider, including asking for a cognitive assessment when memory and/or cognitive processing issues become a concern.		☑	
	2. Provide Alzheimer’s awareness, education and resource materials to public/private work places regarding how to recognize and relate to persons with early stage dementia or their caregivers who are their customers or employees.		☑	
	3. Educate the public, and provide information and resources about, issues specific to persons with younger-onset dementia and their families.		☑	

GOAL 1: INCREASE PUBLIC AWARENESS, ENGAGEMENT AND EDUCATION

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
D. Promote advance care planning and legal and financial planning in the early stages of dementia in order to avoid costly or unnecessary court proceedings and/or guardianships.	1. Educate the public about the need for advance care and end-of-life planning, before cognitive function declines, consistent with the Bree Collaborative End of Life Care Recommendations.	<input checked="" type="checkbox"/>		
	2. Educate the public and caregivers about the need for legal and financial planning – and the importance of obtaining legal and financial advice as a planning tool.	<input checked="" type="checkbox"/>		
	3. Educate the public about ways to protect persons with dementia from abuse and exploitation. Coordinate this outreach with Adult Protective Services, county prosecutors, financial institutions, and other partners.	<input checked="" type="checkbox"/>		
E. Increase public awareness via educational and promotional campaigns developed and implemented collaboratively with the public and private sectors.	1. Engage public relations professional to advise on a promotional campaign to support the awareness of the issues and the implementation of the plan activities.	<input checked="" type="checkbox"/>		
	2. Raise awareness of dementia and available resources by engaging public and private ‘champions’, including faith, business community leaders/corporate and non-profit partners, educators, and health professionals, to assist in developing, implementing and leveraging education and outreach campaigns. Expand the reach of campaigns by identifying and engaging partners that may not be a part of the traditional information service system such as Chambers of Commerce, Employee Assistance Programs, community college and university students.		<input checked="" type="checkbox"/>	
	3. Publicize and promote the online point-of-access portal (See 1.A.1), as well as other points of access (e.g., dementia care navigators, toll free number) for services and supports for persons with dementia and their family caregivers. Utilize social media to build public awareness of available resources.		<input checked="" type="checkbox"/>	

GOAL 1: INCREASE PUBLIC AWARENESS, ENGAGEMENT AND EDUCATION

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
	<ol style="list-style-type: none"> 4. Strengthen and leverage relationships and collaborations between the Alzheimer's Association, the Alzheimer Society, the state's Area Agencies on Aging, and other partners in order to strengthen dementia capable service information systems. 5. Promote outreach to Indian Country through health workers, tribal communications and health fairs. 6. Provide special outreach to individuals with Down syndrome and other people with conditions that are disproportionately impacted by Alzheimer's and their families for short- and long-term planning. 	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/> <input checked="" type="checkbox"/>
F. Increase public awareness about the connections between health and wellness, brain health, and dementia.	<ol style="list-style-type: none"> 1. Inform and educate the public about healthy aging, including links between brain health and nutrition, exercise, stress management and oral health/periodontal disease. 2. Inform and educate the public about the importance of recognizing and addressing the breadth of causes of social isolation in the state's aging population – including sensory loss (hearing, vision), physical disabilities, depression and other forms of mental illness, etc. – and their impact on dementia. 3. Inform and educate the public about the connections between chronic disease (diabetes, heart disease, hypertension, oral health/periodontal disease, sleep disorders, etc.) and dementia. 	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/>		



"...It is very important to raise awareness about the disease with the younger populations, to spread information on how to best avoid the disease and the warning signs of the disease."

A family member in Washington

GOAL 2: PREPARE COMMUNITIES FOR SIGNIFICANT GROWTH IN THE DEMENTIA POPULATION

According to projections by the Office of Financial Management and DSHS, this year nearly 107,000 Washington residents are living with Alzheimer's or related dementia. That figure is expected to grow to more than 270,000 people by 2040. Existing services and facilities cannot keep up with the projected growth, and consequently, more responsibility will be placed on individuals, families and local communities.

The state's public health system can play a key role in helping ensure communities are ready for the projected growth in the number of people affected by dementia. For example, a core element of public health is surveillance, or data collection. Good data drives resource development and asset allocation, and provides the information required to target population needs in a way that anecdotal stories or individual advocacy efforts do not.

Dementia has been traditionally viewed as either an inevitable part of aging or a terminal illness. However, it makes more sense to view dementia as a chronic illness, one that can and will be lived with for many years. As with any condition, if identified early, there are opportunities over time to improve quality of life and care. Early detection is a key factor in improving a person's quality of life.

Public health strives to achieve lasting change in the health of populations,

beyond the treatment of individuals. In the case of dementia, public health seeks to promote healthy aging, including good brain health. While there are not clear strategies to prevent Alzheimer's, there is evidence that what's good for the heart is also good for the brain. And that certain conditions – like vascular disease, high blood pressure, heart disease, and type 2 diabetes – may increase the risk of cognitive decline and Alzheimer's.⁴⁶

To address stigma and the growing numbers of people with dementia, the concept of dementia-friendly communities has emerged internationally. In the United Kingdom and Australia, governments are promoting this concept. In the United States, such campaigns are

What is a Dementia-Friendly Community?

A national initiative was announced at the 2015 White House Conference on Aging - to spread the concept of dementia-friendly communities nationwide.

The Dementia Friendly America initiative describes a dementia-friendly community as one that is informed, safe and respectful of individuals with dementia and their families, provides supportive options, and fosters quality of life.

www.dfamerica.org

emerging through grassroots effort – most notably in Minnesota. Dementia-friendly efforts have also started in Seattle, Washington through a coalition of more than 20 local organizations and community members actively promoting dementia-friendly recreation programs.⁴⁷

The ADWG seeks to involve public and private partners in planning efforts and to infuse age-friendly and dementia-friendly concepts into local communities so that existing resources can reach farther and people with dementia and their families have the information and support they need.

GOAL 2: PREPARE COMMUNITIES FOR SIGNIFICANT GROWTH IN THE DEMENTIA POPULATION

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
A. Attain, analyze, and use available data.	1. Include Healthy People 2020 objectives ⁴⁸ related to persons with dementia, including Alzheimer's in state agencies' strategic plans.	☑		
	2. Implement the Behavioral Risk Factor Surveillance System (BRFSS) cognitive and caregiver modules at least once every three years. ⁴⁹	☑		
	3. Use BRFSS data to understand the human and economic impact of dementia on individuals and family caregivers to inform public health policies, interventions, and development of the Washington State Plan for Healthy Communities and other chronic disease plans.		☑	
	4. Identify and use data to address risk factors for individuals with dementia. Analyze data from public and private sources regarding prevalence of complications and coexisting conditions such as falling, accidents, overmedication, hearing or vision loss, anxiety, depression, financial exploitation, abuse/neglect, fraud, etc.		☑	
B. Include Alzheimer's, dementia and healthy aging in state and local government plans.	1. Integrate goals and objectives related to cognitive impairment, memory loss and dementia into local and state governmental agencies' strategic plans. Such plans include state and area plans on aging, coordinated chronic disease management, falls prevention and emergency preparedness, transportation, and the Washington State Plan for Healthy Communities.	☑		

GOAL 2: PREPARE COMMUNITIES FOR SIGNIFICANT GROWTH IN THE DEMENTIA POPULATION

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
	2. Ensure ongoing activities at Department of Health, such as injury/falls prevention and emergency preparedness, incorporate needs specific to persons with dementia.	☑		
C. Infuse age-friendly and dementia-friendly concepts into local communities.	1. Review emerging models/movements of livable, age-friendly and dementia-friendly communities, and determine elements most critical to developing dementia-friendly communities in Washington State.	☑		
	2. Encourage and incentivize local communities to become more dementia-friendly.			☑
D. Promote healthy aging and brain health.	1. Request that all state and local public health organizations provide content specific to healthy aging, brain health, and Alzheimer's disease/dementia, including Internet links to national, state and local resources.	☑		
	2. Work with UW Healthy Brain Research Network (HBRN) and other partners to develop evidence-based public messages around promoting healthy aging and brain health, while ensuring messages are culturally/ethnically appropriate and designed to reach statewide populations including persons with limited English.		☑	
	3. Promote implementation of evidence-based health promotion programs for people with cognitive impairment and dementia and their family caregivers. Examples may include EnhanceFitness, Chronic Disease Self-Management Program (CDSMP), Reducing Disability in Alzheimer's disease (RDAD), Program to Encourage Active, Rewarding Lives for Seniors (PEARLS), and STAR-C dementia behavior consultation.		☑	
	4. Promote and build upon National Alzheimer's Plan education and awareness campaigns as available.	☑		
	5. Partner with community organizations to disseminate evidence-based educational materials for the public around healthy aging		☑	

GOAL 2: PREPARE COMMUNITIES FOR SIGNIFICANT GROWTH IN THE DEMENTIA POPULATION

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
	and accessing health care proactively. Include organizations such as tribal centers, community and senior centers, faith-based organizations, hospitals and health plans, YMCAs and parks departments, secondary schools and institutes of higher learning.			



"I would like to be able to keep my loved one home with me as long as possible. I will take the best of care for her. The problem is getting the house prepared for her safety.

[We need] more services that help us with solutions to avoid nursing homes and assisted living before we are ready."

A family member in Washington

GOAL 3: ENSURE WELL-BEING AND SAFETY OF PEOPLE LIVING WITH DEMENTIA AND THEIR FAMILY CAREGIVERS

While the extent of elder abuse is unknown, the National Center on Elder Abuse estimates that between 2 and 5 million elders (65+) experience some sort of abuse each year. Older adults living with dementia are thought to be at higher risk for neglect, abuse and exploitation – this can take the form of self-neglect, neglect, physical or sexual abuse or exploitation.⁵⁰ People with dementia are also more susceptible to financial exploitation by family members and friends, paid providers, legal guardians, and other fiduciaries. Additionally, strangers may seek out vulnerable adults through elaborate mail, telephone, and internet scams.

Increased awareness and education is a key component of many of the recommendations for this goal.

“Gatekeepers”, such as emergency responders, bank tellers, postal workers and neighbors are often the first to see signs that something might be wrong.

While local programs for addressing abuse and neglect for people with dementia exist, such as Elder Justice Center in Vancouver, they are limited, typically concentrated in urban settings, and less available in rural areas.

A key message we heard repeatedly from people with early-stage Alzheimer’s is how important it is to create a plan while you can, selecting trusted people to help manage and implement their wishes for health care, finances and other important decisions when the time comes to need help. Early planning and the use of supported decision-making provides critical reassurances and helps alleviate anxiety as the disease progresses.

The Washington State Supreme Court is engaging in a community partnership to improve adult guardianship practices. The pilot project, Working Interdisciplinary Networks of Guardianship Stakeholders (WINGS) seeks to improve judicial processes, better protect individual rights, and promote fiduciary standards and guardian accountability. This is an example of ongoing and emerging work that is critical to creating dementia-capable communities in our state.

Other safety concerns arise from behaviors commonly seen in people with dementia. Behaviors such as wandering, resisting care, and poor judgment place the person with dementia, their

“As a financial professional, and the daughter of parents experiencing memory losses, I would like to see more emphasis on offering classes and information to people who are caring informally for their aging parents. For example, the forensics of finances and how to take over or assist parents with finances, avoid scams and create spending plans built around their values before it is too late.”

A family member in Washington

caregivers, and others at risk. For example, the decision about when to give up driving is a source of distress for both individuals and families.

GOAL 3: ENSURE WELL-BEING AND SAFETY OF PEOPLE LIVING WITH DEMENTIA AND THEIR FAMILY CAREGIVERS

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
A. Increase awareness to reduce the risk for neglect, abuse, and exploitation of people with memory loss.	1. Incorporate content about dementia (warning signs, the importance of early detection and diagnosis), the heightened risk of abuse, neglect, and exploitation; and about community resources into the Community Health Worker training.	☑		
	2. Update and expand the Gatekeeper Program through Area Agencies on Aging (AAAs) or aging service partners to aid in identifying and assisting people experiencing abuse, neglect or exploitation.		☑	
	3. Increase awareness of existing consumer protection education and outreach, such as AARP and AGO fraud alert networks.		☑	
B. Promote in-home and community safety, and the quick return of people with dementia who may wander.	1. Compile and make accessible educational materials about ways to improve safety for people with dementia. Information may address falls prevention, wandering, disaster preparedness, and home safety assessments.	☑		
	2. Increase public and provider awareness of programs designed to identify and locate people with dementia who may wander, such as Safe Return, Comfort Zone and Silver Alert.	☑		
	3. Promote and disseminate training for first responders about dementia. Information may address: recognizing signs and symptoms, communication skills, understanding behaviors including wandering, community resources, and red flags of neglect and abuse.		☑	

GOAL 3: ENSURE WELL-BEING AND SAFETY OF PEOPLE LIVING WITH DEMENTIA AND THEIR FAMILY CAREGIVERS

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
C. Enhance legal protections for people living with dementia.	1. Make more readily available appropriate forms for legal planning such as Durable Power of Attorney for Health Care, Durable Power of Attorney for Finances, Advance Directives, and information about a Physical Order for Life Sustaining Treatment (POLST) at no cost to consumers through public libraries, resource centers, online, and other appropriate locations.	☑		
	2. Encourage the use of multi-disciplinary teams such as Elder Justice Centers statewide to ensure coordinated efforts and improved communication with law enforcement, Adult Protective Services, local prosecuting attorney's offices, and advocacy groups.	☑		
	3. Promote existing and emerging opportunities to educate financial institution staff about dementia and possible financial exploitation and abuse, their authority to report suspected abuse, and the protections for those who report. For example, "Spotting Financial Exploitation" from the Attorney General's Office.	☑		
	4. Explore legislation to expand the categories of people who qualify as mandatory reporters for exploitation and abuse.		☑	
	5. Convene a workgroup to evaluate current statute and regulations that affect people with dementia, specifically those regarding powers of attorney, guardianship, payeeships, trusts and wills to: (a) Decrease fraud, abuse, neglect and self-neglect and the enrichment of wrongdoers through undue influence; and (b) Maximize autonomy and independence of individuals with dementia.			☑
	6. Explore screening tools that may be used by APS, law enforcement, and other entities to identify diminished capacity and cognitive impairment. [In progress]	☑		

GOAL 3: ENSURE WELL-BEING AND SAFETY OF PEOPLE LIVING WITH DEMENTIA AND THEIR FAMILY CAREGIVERS

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
D. Promote practices to ensure driving safety of individuals with memory loss and/or dementia.	<ol style="list-style-type: none"> 1. Convene a workgroup, to include a representative of the Department of Licensing, to evaluate policies and best practices for promoting safe driving in people with dementia. 2. Compile and make accessible educational materials about ways to discuss and address driving issues, including how to work with the Department of Licensing. 3. Encourage and promote establishment of voluntary Safe Driver Assessment programs, potentially including Occupational Therapy expertise, at hospitals, diagnostic assessment centers and major rehab centers. 	<div> <input checked="" type="checkbox"/> </div>	<div> <input checked="" type="checkbox"/> </div>	

"My mom was diagnosed 7 years ago and she is still driving, she refuses to stop even at the "recommendation" of her doctor... My dad had a Safe Driving Evaluation done at Good Sam before they discontinued them. I paid \$425.00 out of pocket; after a thorough exam by a Driver Rehabilitation Specialist, he 'retired', stopped driving. Sadly, Good Sam no longer offers the safe driving evaluations because insurance companies do not find them medically necessary."

A Washington caregiver



GOAL 4: ENSURE ACCESS TO COMPREHENSIVE SUPPORTS FOR FAMILY CAREGIVERS

Family caregivers are the rock upon which long-term supports and services are built. They provide the majority of care for people with dementia. In this plan, family caregivers are defined broadly as unpaid caregivers who have a close familial or personal relationship to the person with dementia. They include spouses, domestic partners, friends and neighbors, children, extended family – anyone with a caring connection to the person and significant uncompensated responsibility for providing care.

Given the expected increases in the state’s dementia population, and significant funding constraints for new services, we must provide comprehensive supports for family caregivers. Not all caregivers have the same experiences, and the supports individual caregivers need vary widely. There is also a need to make education and supports accessible in terms of language and cultural appropriateness, and to reach caregivers in the rural areas of Washington. The National Plan to Address Alzheimer’s Disease recognizes these challenges. For example, the federal government is working to connect American Indian and Alaska Natives to Alzheimer’s disease resources.⁵¹

There are some commonalities among all caregivers. First and foremost, caregivers expressed a need to know what to expect in their journey caring for a person with Alzheimer’s and other dementias. Caregivers also need to know what is “out there” to help them when they need support and they want culturally relevant advice, support, and services. Some caregivers need a periodic break – to do grocery shopping, attend to their own health or well-being, or even to get a full night of sleep. They want to have someone to turn to when they need advice or a compassionate ear.

*“[We need] more training and information on how to assist people with dementia to have the highest quality of life possible. Increase use of innovative programs like **Music & Memory** in which an individualized music playlist is created for the individuals. Overall, less focus on the disease and curing it and more focus on partnering with the people living with it to live life to their fullest.”*

A family member in Washington

Mostly, caregivers need a “roadmap” – what to expect as the disease progresses. Each family’s situation is unique, and the supports a family caregiver will need vary depending upon the family’s situation. However, during the statewide listening sessions we often heard from those in attendance about the need for help understanding what basic services and supports are available, options to help families before they reach the end of their rope, and caregiver supports to be made available across the state, rather than concentrated in urban areas.

Across the state, people told us how important support groups were to their ability to continue to provide care. Family members credited support groups with helping them learn how to better address support needs and learn about behavioral interventions. Family members also stressed how much their support group helped with their mental and emotional health. Respite care was a crucial support request for many.



A recent expansion of Washington State's Family Caregiver Support Program demonstrated the ability to delay an individual's transition to Medicaid long-term care services. When access to FCSP services increased, utilization of Medicaid LTC decreased. This occurred despite the fact that more expansion caregivers were already enrolled in Medicaid medical coverage.⁵²

Washington State is currently working with the federal Center for Medicare and Medicaid Services (CMS) on a Medicaid Transformation Waiver that includes components related to long term services and supports. If approved, this would (1) offer a new benefit package for individuals who are eligible for Medicaid but are not currently accessing Medicaid-funded LTSS. This benefit package will primarily support unpaid caregivers, avoiding or delaying the need for more intensive Medicaid-funded services; and (2) establish a new eligibility category and

benefit package for individuals "at risk" of future Medicaid LTSS use who currently do not meet Medicaid financial eligibility criteria. This is designed to help individuals avoid or delay impoverishment and the need for Medicaid-funded services. More on the **Medicaid Transformation Waiver** may be found on the Health Care Authority website.

A common trend is for families to wait for a crisis to reach out for support. However we have seen families experience more success in using services when they reach out earlier - before a crisis occurs. Early engagement with education and support groups helps families understand and accept what is happening, which in turns helps them navigate the progression of supports a person with dementia may need over time.

GOAL 4: ENSURE ACCESS TO COMPREHENSIVE SUPPORTS FOR FAMILY CAREGIVERS

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
A. Provide guidance and support for dementia caregivers in navigating service systems.	1. Create a Washington State-specific “road map” for family caregivers providing information about what to expect over time to help plan for the future.	☑		
	2. Provide dementia-specific information and assistance for family caregivers of people living with dementia.	☑		
	3. Increase awareness of both public and private programs that offer professional guidance in understanding the diagnosis and how to access services and plan for the future.	☑		
B. Increase availability of and access to education and support services.	1. Increase availability of evidence-based programs for people with dementia and their family caregivers, e.g. STAR-C, Reducing Disability in Alzheimer’s disease (RDAD), early stage memory loss groups and Powerful Tools for Caregiving, and expand supportive services such as behavior consultation, counseling, flexible family supports, adult day services, etc.		☑	
	2. Increase availability and delivery systems of education for family members about dementia communications skills, understanding and responding to non-verbal cues and behaviors, and home care activities such as assuring home safety, managing medications, using effective approaches for personal care and oral health needs, addressing hearing loss and other sensory deficits, and incorporating physical and meaningful activity into the day.		☑	
C. Increase availability of and referral to support groups for caregivers.	1. Explore strategies to expand support groups, particularly in rural areas.	☑		
	2. Expand and promote implementation of early stage memory loss groups for people with cognitive impairment/dementia and their care partners.	☑		

GOAL 4: ENSURE ACCESS TO COMPREHENSIVE SUPPORTS FOR FAMILY CAREGIVERS

Strategy	Recommendations (<i>needed policies or responses</i>)	Short	Mid	Long
D. Increase access to respite.	<ol style="list-style-type: none"> Promote education and coaching around utilizing natural support networks and care teams to support the person with dementia and the family caregiver. Expand funding for respite care, and explore flexible service models, such as overnight care, drop-in day care, volunteer-based programs, crisis/emergency respite, and models that promote wellness, e.g., Memory Care & Wellness Services. 		<input checked="" type="checkbox"/> <input checked="" type="checkbox"/>	
E. Reach individuals and family members early in the disease process through collaborative models of social engagement.	<ol style="list-style-type: none"> Develop information about models of social engagement such as Alzheimer’s Cafes, Zoo Walks, Museum/Arts (“here:now”) programs, etc. Disseminate and promote development of collaborative models of social engagement and dementia-friendly recreation throughout the state. 	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/>		
F. Increase the number of culturally and linguistically diverse caregivers who participate in education and support programs.	<ol style="list-style-type: none"> Identify and engage leaders and organizations of diverse populations to explore needs for education and support. Identify and make educational programs and support services for diverse caregivers more available across the state. 	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	

GOAL 4: ENSURE ACCESS TO COMPREHENSIVE SUPPORTS FOR FAMILY CAREGIVERS

Strategy	Recommendations (<i>needed policies or responses</i>)	Short	Mid	Long
G. Collaborate with tribes to meet unique needs of Native American family caregivers living with dementia.	1. Engage tribal representatives to explore the needs of tribal families caring for people with dementia to develop culturally relevant supports and services.	☑		
H. Develop supports for family caregivers who are employed, caring for people with developmental disabilities and dementia, and those living with younger-onset dementia.	1. Increase awareness among the public and community agencies that the Family Caregiver Support Program is available and helps caregivers of people with dementia at any age. 2. Inform caregivers and patients about the Family and Medical Leave Act, long-term care insurance, the benefits of advance legal and financial planning, and existing support programs through agency websites, educational forums, service networks, and the media. 3. Educate professionals working with families of people with younger-onset Alzheimer's, including those in the developmental disabilities system, about the special challenges, issues and resources available for support. 4. Assess barriers and best practices for individuals and families living with younger-onset Alzheimer's and develop strategies to enhance support. 5. Provide education and supports for older family caregivers who provide primary care for their adult children or siblings with developmental disabilities and dementia. 6. Engage employers and those responsible for developing and implementing Employee Assistance Programs about the issues facing family caregivers and encourage them to incorporate policies such as flextime, telecommuting, referral services, and on-site support programs.	 ☑ ☑	 ☑ ☑ ☑	

GOAL 4: ENSURE ACCESS TO COMPREHENSIVE SUPPORTS FOR FAMILY CAREGIVERS

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
I. Expand tele-health and web-based resources for family caregivers.	1. Identify and promote opportunities to bring tele-health and web-based resources to more family caregivers, particularly in rural areas.			<input checked="" type="checkbox"/>

Nine benefits of early diagnosis:

1. **Optimize current medical management**—attention to treatable causes, exacerbating factors, and medication review.
2. **Relief gained from better understanding**—validation of concerns, and a framework for understanding the origin and nature of symptoms.
3. **Maximize decision-making autonomy**—the chance to make important decisions about the future while still retaining mental capacity.
4. **Access to services**—timely access to medical care, advice and support, all of which require a diagnosis.
5. **Risk reduction**—safety at home, driving assessments, anticipating and avoiding adverse effects of medications.
6. **Plan for the future**—early retirement, financial planning, safety and security issues.
7. **Improve clinical outcomes**—slowing or stabilizing cognitive and functional decline (slow progression of cognitive and functional impairment).
8. **Avoid or reduce future costs**—chiefly through delaying or avoiding transition into a care home.
9. **Diagnosis as a human right**—both to have access to an accurate diagnosis, and to be informed of it or not, according to one's preference.

The World Alzheimer's Report 2011 published by Alzheimer's Disease International

GOAL 5: IDENTIFY DEMENTIA EARLY AND PROVIDE DEMENTIA-CAPABLE EVIDENCE-BASED HEALTH CARE.

There are many benefits to early detection and diagnosis of Alzheimer's. Of primary importance is that it allows for some forms of cognitive impairment - such as those caused by a vitamin B12 deficiency, medication interactions or depression - to be identified and reversed. While there's still no way to cure or slow the progression of Alzheimer's disease, an early formal diagnosis offers opportunities for better outcomes.

Early detection and diagnosis offers individuals and their families a "reason" or way to understand the changes that have been occurring, which is often a relief. It also allows families time to adapt to changes, to get legal and financial affairs in order, to participate in research, and gives an opportunity to engage in advance planning. Early detection offers health care providers key information to reduce poor health outcomes and prevent emergencies for both the individual and their family caregivers.

Fewer than half of the people who meet diagnostic criteria for dementia have received a diagnosis.

(Bradford, Kunik, Shultz, Williams, & Singh, 2009)

Although there are many benefits to early detection, estimates indicate that fewer than half of the people who meet diagnostic criteria for dementia have received that diagnosis from a physician.^{53, 54}

One of the main issues identified from both the ADWG surveys and the public listening sessions was how difficult it was to obtain a diagnosis for many people facing possible dementia. For most, it took multiple visits with physicians and specialists over many months to arrive at a possible diagnosis. Both diagnosis and care quality varied widely depending upon the person's provider and location. Rural residents found it especially difficult to access specialists.

Furthermore, there was wide variability in referrals to local services and supports after diagnosis.

Compared to individuals without dementia, people with dementia have as many or more serious co-occurring conditions, take more medication, and are more likely to be hospitalized than individuals of the same age without dementia. Individuals with dementia may also be less able to manage their medical and/or behavioral conditions – which contributes to a decline in the individuals'

Many steps toward dementia-capable systems can be implemented now, supported by new national policies favoring early detection, care planning and coordination, support for caregivers, and measurement of care quality.

(Borson & Chodosh, 2014)

abilities to carry out daily activities.⁵⁵ In addition, the high prevalence of hearing loss in older adults may complicate identification and or treatment as cognitive testing and follow up often relies heavily on a person’s ability to hear and respond to questions and instructions.

In the ADWG Primary Care survey, practitioners indicated a lack of familiarity with Medicare’s Annual Wellness Visit benefit which includes the provision for cognitive assessment. And, they expressed significant interest in identifying brief, validated cognitive screening tools they could use in their practice when a patient expresses concern with memory loss or other signs of potential dementia. Physicians also indicated that in many practices across the state, no guidelines to ensure quality care related to screening, diagnosis, or treatment are in place.

“Dementia-capable” health care systems are those “that provide individualized, coordinated, and integrated medical and psychosocial care for patients and their care partners, delivered by cohesive teams of clinicians, staff, and health care administrators.”⁵⁶

To improve care quality and prepare for the future growth of this population in our systems, it is critical to integrate dementia-capable best practices to detect cognitive impairment, make and disclose timely diagnosis, coordinate care for wellness and to manage co-occurring conditions, provide early and ongoing education and support of family caregivers, and address the need for advance planning while cognitive capacity exists. Potential for improvement might be found in building upon emerging efforts such as Healthier Washington and/or by expanding reimbursement codes that support patient planning and counseling.

GOAL 5: IDENTIFY DEMENTIA EARLY AND PROVIDE DEMENTIA-CAPABLE EVIDENCE-BASED HEALTH CARE.

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
A. Endorse a set of evidence-based standards of care for dementia to promote high quality health care.	1. Convene an expert panel to identify and endorse a set of evidence-based standards for diagnosis, treatment, supportive care and advance planning for people with dementia.	<input checked="" type="checkbox"/>		
	2. Identify and endorse a framework for dementia care that would include evidence-based practice standards and meet the needs of persons with dementia, their care partners and clinicians.		<input checked="" type="checkbox"/>	
	3. Educate and facilitate integration of a ‘dementia care framework’ that targets patients with multiple chronic conditions into existing and emerging initiatives and practices. ⁵⁷			<input checked="" type="checkbox"/>

GOAL 5: IDENTIFY DEMENTIA EARLY AND PROVIDE DEMENTIA-CAPABLE EVIDENCE-BASED HEALTH CARE.

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
B. Promote early detection, diagnosis and treatment.	1. Encourage regular screening of cognitive status for older adults in primary care settings, considering cognitive status as a ‘vital sign’, similar to tracking blood pressure in heart disease.	☑		
	2. Identify and recommend several validated, brief cognitive screening tools.	☑		
	3. Promote timely assessment and disclosure of cognitive impairment and/or diagnosis of dementia through the identification of a diagnostic pathway for use in primary care settings.	☑		
C. Develop a dementia capable, culturally competent primary care workforce throughout the state.	1. Establish minimum educational requirements for all trainees in health related fields in order to integrate foundational knowledge required for providing dementia care. ⁵⁸		☑	
	2. Request the regents of UW medical school and other institutions of clinical education expand dementia care education in their core curriculums and create interdisciplinary educational experiences related to the long-term management of dementia care.		☑	
	3. Partner with licensing boards to promote continuing education on evidence-based guidelines around early detection and diagnosis of cognitive impairment, dementia care interventions and management of the disease.		☑	
	4. Partner with professional organizations and academic settings to develop or increase the availability of affordable continuing education/training programs.		☑	
	5. Promote the use of incentives such as, but not limited to, loan forgiveness for clinicians going into geriatrics.			☑
	6. Promote use of tele-health by aligning with efforts of the statewide tele-health workgroup convened by DOH. Utilize such technology to provide care directly for individuals with dementia and/or to support a consultative role			☑

GOAL 5: IDENTIFY DEMENTIA EARLY AND PROVIDE DEMENTIA-CAPABLE EVIDENCE-BASED HEALTH CARE.

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
	with providers and care teams such as the Impact model or the Echo model.			
	7. Partner with organizations like the Washington Healthcare Improvement Network (WHIN), practice transformation initiatives and/or clinical associations to disseminate evidence-based guidelines across the state.		☑	
D. Support development and implementation of dementia related outcome-based performance measures.	1. Endorse a set of dementia specific performance metrics for the individual with dementia and their care partner to drive improvements in care practice. ⁵⁹		☑	
	2. Promote the inclusion of endorsed dementia related metrics within measurement sets of health systems and health reform efforts such as the Healthier Washington Practice Transformation work.			☑
	3. Advocate for the collection, documentation and dissemination of the prevalence of individuals with cognitive impairment and dementia in clinical practices and health systems.			☑
	4. Promote the use of value-based reimbursement by employer groups and public/private health plans for clinics showing improvement in dementia care outcomes-based performance metrics.		☑	
E. Support policies that promote the capacity of primary care to adequately screen, diagnose, counsel, and treat patients with cognitive impairment/dementia.	1. Promote understanding and effective utilization of (a) Medicare Annual Wellness Visit which includes objective cognitive assessment/screening; and (b) Complex care management (CCM) codes for care coordination services, and advance care planning codes for individuals at end of life. See Bree Collaborative End of Life Care Recommendations .	☑		
	2. Advocate for the development of, and promote use of billing codes and reimbursement for care that improves the health and lives of older adults (e.g., care coordination, patient planning and counseling around care, safety and end of life, etc.)		☑	

GOAL 5: IDENTIFY DEMENTIA EARLY AND PROVIDE DEMENTIA-CAPABLE EVIDENCE-BASED HEALTH CARE.

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
	3. Request and encourage the Dr. Robert Bree Collaborative to address cognitive impairment and dementia care.			☑
F. Increase awareness of the challenges associated with dementia and co-occurring conditions.	1. Educate the clinical community on the impact and management of dementia and co-occurring chronic conditions. ⁶⁰ Once identified, cognitive impairment and dementia should become an organizing principle for all other care of the patient. ⁶¹		☑	
	2. Educate the clinical community, and include in guidelines, information on how sensory loss such as hearing, vision, and balance impacts the diagnosis and/or treatment of the cognitively impaired patient.		☑	
	3. Promote practices and initiatives that facilitate early enrollment into palliative and hospice care to support individuals with worsening dementia and their care partners.	☑		
G. Reduce preventable emergency department visits, hospitalizations and readmissions by improving communication and transitions of care.	1. Increase awareness among primary care clinicians and care partners of potentially avoidable causes of ED visits, hospital admissions and readmissions for people with cognitive impairment and dementia. Emphasize the importance of partnership and communication between clinician and care partners.		☑	
	2. Increase awareness of care coordination and clinic-based health navigation and its potential to improve communication and transitions of care for individuals with dementia.		☑	
	3. Support existing and emerging efforts to increase care coordination and care transitions services in clinical practices for individuals with dementia.			☑
	4. Identify and disseminate guidelines/protocols for care coordinators and clinic-based health navigators in working with individuals with dementia. ⁶²			☑

GOAL 5: IDENTIFY DEMENTIA EARLY AND PROVIDE DEMENTIA-CAPABLE EVIDENCE-BASED HEALTH CARE.

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
H. Improve understanding of and response to challenging and/or complex behaviors.	1. Convene a workgroup to conduct an environmental scan to identify supports, trainings and needs in the community for addressing challenging behaviors with individuals with dementia.	☑		
	2. Create and/or provide informational tools and resources ⁶³ for practice teams to provide to care partners about understanding and responding to behaviors associated with dementia, to include use of non-pharmacological approaches and reducing use of potentially harmful psychoactive drugs		☑	
	3. Investigate models of behavior and crisis support that might be replicated across the state (e.g., King County's Geriatric Regional Assessment Team (GRAT) - funded largely by mental health state levy tax).	☑		
	4. Create a network of trainers or resources (speaker's bureau) to assist health providers and care teams in effectively responding to individuals with challenging behaviors.			☑
I. Increase primary care workforce awareness of the critical role of care partners/caregivers.	1. Increase awareness of the need to involve care partners/caregivers in every step of care planning and goal setting for the person with cognitive impairment and dementia.		☑	
	2. Increase clinician awareness about regular systematic assessment of care partner stress, ability, knowledge and skills to provide care.			☑
	3. Prepare and disseminate simple documents for clinical teams that identify community resources and educational information that are available to support care partners of people with dementia.			☑



"I would like to see the void in behavioral services for dementia have more attention. Physicians in adult medicine need to have awareness and education on how to help families that are caring for seniors with dementia. Geropsych services need to be available on an outpatient basis to help families, assisted livings, adult family homes and skilled nursing when seniors are escalating in behaviors to prevent the catastrophic events."

A health care provider in Washington

"Hearing loss has been connected to the onset and progression of dementia. Hearing Loss and Dementia behaviors mimic each other and could lead to misdiagnosis. Untreated hearing loss could create more problems as well as being a barrier to treatment."

A hearing loss advocate in Washington

"Make diagnosis easier, physicians tend to refer to neurologists, and this is good for the imaging and ruling other things out, but families don't get a definitive diagnosis or helpful information from neurologists.

Psychologists and primary care practitioners should be able to do this type of exam routinely and not shy away from it by referring to specialists."

A family member in Washington

GOAL 6: ENSURE DEMENTIA-CAPABLE LONG-TERM SERVICES AND SUPPORTS ARE AVAILABLE IN THE SETTING OF CHOICE

Most people want to stay in their homes and their communities until they die. Most families want to take care of their loved ones with Alzheimer's at home. However, individual needs and preferences vary widely.

Survey respondents and public listening session participants expressed deep concern about the high expenses associated with dementia care, and the impacts of care costs on families. Individuals must contribute most of their resources before becoming eligible for Medicaid. In many instances, the cost of any external support is far outside the ability of the individual or family to afford. The ADWG feels that exploring viable options for the financing of the cost of long-term care is critically important for Washington families. Another concern raised varying degrees of care quality, and challenges associated with care coordination for people with dementia. There was a strong, unified voice advocating for better dementia-related training for LTSS workers.

Providing the best care and support will only happen when service providers can identify people with dementia. It's important that staff providing assistance learn to recognize people with possible dementia and offer appropriate referrals. The federal Administration for Community Living describes this part of a "dementia capable" system as one that: identifies people with possible dementia and recommends that they see a physician for diagnosis; educates staff to understand the symptoms of dementia; communicates effectively with people with dementia and their caregivers; and provides services that are person- and family-centered.

Washington State has developed a strong long-term supports and services (LTSS) system both in the private and public market place. In spite of its strengths, gaps do exist for people with dementia and their caregivers. For example, while specific requirements related to providing

"It is crucial that paid caregivers or adult family home/assisted living staff truly are trained in how to care for someone with dementia. The amount of training now is not enough and not thorough enough."

A Washington caregiver



“specialized dementia care” are defined for Specialized Dementia Care Medicaid-contracted assisted living facilities, under WAC 388-110-220 (3), such specialized dementia care standards are not defined for facilities marketing such services to private pay consumers. Without action, these gaps will continue to grow.

The ADWG identified several strategies and recommendations designed to improve dementia-capability, support aging in place, delay or avoid placement in a long-term care facility, and reduce barriers to accessing palliative/comfort care.

GOAL 6: ENSURE DEMENTIA-CAPABLE LONG-TERM SERVICES AND SUPPORTS ARE AVAILABLE IN THE SETTING OF CHOICE

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
A. Enhance coordination of care.	1. DDA, ALISA, HCA, and DOH should each designate an Alzheimer’s program coordinator to improve communication and collaboration among these agencies.	☑		
	2. Identify and promote existing models of care coordination services for individuals living in the community and their family caregivers, such as Health Homes, geriatric care managers, and Alzheimer’s Association Care Navigators.	☑		
	3. Convene a workgroup to identify and seek funding to support best practice dementia capable models that minimize care transitions, including emergency room visits, hospital admissions and readmissions.	☑		
	4. Provide dementia-capable information and assistance for people living with dementia to help them remain in the community. [In progress]	☑		
B. Expand access to affordable care to delay nursing home placement and spend-down to Medicaid.	1. Support a robust array of community-based services to include adult day care and evidence-based practices such as Memory Care & Wellness, STAR-C, etc.		☑	
	2. Evaluate the potential for specialized dementia care services in adult family homes to determine cost-effectiveness, standards, training, services, rates, and oversight needs.		☑	
	3. Undertake a review of Medicaid rates for specialized dementia care in assisted living facilities.		☑	

GOAL 6: ENSURE DEMENTIA-CAPABLE LONG-TERM SERVICES AND SUPPORTS ARE AVAILABLE IN THE SETTING OF CHOICE

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
C. Strengthen numbers and effectiveness of LTSS workers.	1. Enhance Dementia Specialty Training available to LTSS workers for all settings.		<input checked="" type="checkbox"/>	
	2. Ensure training and testing for all LTSS workers is more readily available throughout the state.		<input checked="" type="checkbox"/>	
	3. Ensure certification of all LTSS workers is more achievable for limited English speakers.	<input checked="" type="checkbox"/>		
	4. Increase dementia-capability of HCS/AAA Case Management staff by enhancing Core training to include more information around the importance of early detection and diagnosis, responding to behaviors, and assessing and addressing hearing loss and other sensory limitations.		<input checked="" type="checkbox"/>	
	5. Elevate the status of LTSS workers by establishing a geriatric and/or dementia certification for LTSS workers, such as a gerontology scholar program.			<input checked="" type="checkbox"/>
D. Reduce the burden of long-term care costs on families and the state.	1. Support a study commissioned by the State on public/private long-term care financing models and subsequent efforts to improve the financing for public LTSS. [In progress]	<input checked="" type="checkbox"/>		
	2. Identify tools and strategies to more effectively coordinate current systems and seek federal funding opportunities to help meet the costs of financing care, such as the federal Medicaid Transformation Waiver .	<input checked="" type="checkbox"/>		
	3. Increase operations research capacity at ALTSA to support data-driven evaluation and planning.			<input checked="" type="checkbox"/>
	4. Encourage parity in coverage options in all health insurance plans in regard to diagnosis and ongoing support/treatment of persons with dementia.			<input checked="" type="checkbox"/>
E. Improve the quality of long-term services and supports for people with dementia.	1. Promote systematic documentation of people's choices for end-of-life care prior to or upon entry into a LTSS setting.		<input checked="" type="checkbox"/>	
	2. Explore barriers and possible solutions to accessing hospice and palliative care for people with dementia.		<input checked="" type="checkbox"/>	

GOAL 6: ENSURE DEMENTIA-CAPABLE LONG-TERM SERVICES AND SUPPORTS ARE AVAILABLE IN THE SETTING OF CHOICE

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
	<ul style="list-style-type: none"> 3. Convene a workgroup to define and promote dementia care quality standards and outcome measures for Washington long-term care settings, to include standards for settings advertising themselves as “memory care” and/or “specialized dementia care”. 4. More adequately fund the Long-Term Care Ombuds Program (LTCOP) to serve vulnerable people in all settings and enhance LTCOP volunteer capability to address issues relating to care and treatment of those with dementia. 5. Strengthen the capacity for Adult Protective Services caseworkers to serve people with dementia by developing tools and enhancing skills for determining capacity and the need for guardianship. [In progress] 6. Expand the authority of the Office of Public Guardianship to assist individuals with planning end of life care and decision-making, and provide funding to meet the need. 	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
F. Increase awareness of assistive technologies that promote independence for people with dementia and support for family caregivers.	<ul style="list-style-type: none"> 1. Identify and promote the use of assistive technologies that assist with independence, safety and aging in place. This might include low-or high-tech devices such as assistive listening devices or hearing aids, alert systems, medication aids or reminders, identification jewelry, locating devices, etc. 2. Create a resource guide/toolkit that describes assistive technologies and equipment relevant for memory loss and dementia. 	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	

GOAL 7: PROMOTE INNOVATION AND RESEARCH RELATED TO CAUSES OF AND EFFECTIVE INTERVENTIONS FOR DEMENTIA

All of the strategies and recommendations above focus on alleviating or managing the impacts of dementia on people and their families. Respondents to the ADWG survey indicate that research on prevention is also a critical issue that Washington State should address. The National Alzheimer's Plan has made progress in attaining funding for research but we still do not have interventions that stop or slow Alzheimer's. New research, with promising results, is occurring regularly.

A huge challenge to Alzheimer's research is finding enough volunteers to translate basic research into clinical studies and clinical trials.

Moving from basic research to clinical settings requires participation in clinical trials, communication and dissemination of the results throughout the medical community, and long-term data collection and analysis.

The State has a role to play in making sure that people with early stage dementia are made aware of opportunities to participate in research, in leveraging resources, and in providing data and communicating results. Other disease-model plans have shown success in reducing disease burden among Washington residents.

"Two of the major stumbling blocks researchers face are lack of participation and slow enrollment in treatment trials.

If we're going to develop effective treatments for Alzheimer's disease, we need to enroll people in studies who are normal but have the biological characteristics that may predispose them to Alzheimer's disease. You do this by getting thousands of people involved."

Dr. Peterson, chair of the National Advisory Committee on Research, Care and Services for the National Alzheimer's Project Act

GOAL 7: PROMOTE INNOVATION AND RESEARCH RELATED TO CAUSES OF AND EFFECTIVE INTERVENTIONS FOR DEMENTIA

Strategy	Recommendations <i>(needed policies or responses)</i>	Short	Mid	Long
A. Increase support for basic, clinical and translational research around cognitive health, dementia and effective dementia care.	<ol style="list-style-type: none"> 1. Explore ways to improve the infrastructure for supporting basic, translational, and clinical research in the state. 2. State and local agencies will explore funding opportunities and collaborations for Washington to participate in dementia care service innovation programs. 3. Leverage the metrics from health information exchanges as they become available, to support research efforts at the clinic level. 	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/>	
B. Develop relationships with key community stakeholders to assess and pilot culturally specific/ relevant services.	<ol style="list-style-type: none"> 1. Identify organizations and institutions in WA involved in providing dementia related psychosocial and medical services, and connect them with AD research to promote research awareness and strategic alliances, and explore using as pilot sites. 	<input checked="" type="checkbox"/>		
C. Increase number of research participants.	<ol style="list-style-type: none"> 1. Educate the public, including people with cognitive impairment, on the availability, purpose, and value of research and encourage participation in a broad spectrum of dementia research (i.e., research on finding a cure, prevention, improving the quality of life for individuals and caregivers). 2. Engage community clinicians to encourage patient referral to and participation in clinical trials and dementia related research and provide examples of 'how to have the conversation'. 3. ADWG partners to host a collaborative Alzheimer's Summit highlighting research and best practices related to the Alzheimer's State Plan goals. 	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	

CONCLUSION AND NEXT STEPS

Alzheimer's disease and other dementias profoundly impact our entire community. The projected increase in Alzheimer's disease and other dementias in Washington State will bring enormous challenges to individuals, families, businesses, local communities and the state.

A national effort to prepare for this increasing public health issue is also underway. The U.S. Department of Health and Human Services released the first *National Plan to Address Alzheimer's Disease* in 2012. The Centers for Disease Control, the National Institutes of Health and the Administration for Community Living are working with voluntary health organizations to reduce the risk for dementia through the promotion of brain health and to improve care and support for people with dementia. This plan complements and builds upon these efforts.

POTENTIAL IMPACT OF THIS PLAN

This plan identifies gaps between the needs of individuals and the services available, potential strategies, short- and long-term goals, and provides a starting point as we prepare for the future. This plan recognizes opportunities to make positive changes, offering hope for living better with dementia by promoting early detection and better management of the disease, protecting persons with dementia from abuse and exploitation, expanding cost-effective services for people with dementia and their family caregivers, preparing communities for dementia, and improving the dementia-capability of long-term supports and services.

The vision put forth in this plan will improve care for individuals, and help reduce growing costs and burdens related to dementia. Examples include:

Delaying the need for higher cost care

Increased public awareness of dementia and available resources will enable individuals and families to more easily access information and support services, helping them to care for individuals longer at home or in the community.

Avoiding preventable emergencies and hospitalizations

Early detection and diagnosis, accompanied by timely education for individuals and families, will assist them to better manage care needs.

Reducing unnecessary court proceedings or guardianships, and unwanted invasive care near the end of life

Education about legal, financial and advance care planning will increase the number of individuals with tools to guide substitute decision-making.

Postponing or preventing movement to Medicaid

Expanding family caregiver supports will help individuals with dementia to stay at home.

While detailed information around the return on investment for some approaches may need more research over time, the strategies and recommendations are designed to help slow the growth in costs associated with dementia care, and improve the quality of life and care for Washingtonians with dementia and their families.



IMPLEMENTATION OF THE ALZHEIMER'S PLAN

Washington State's Alzheimer's Plan was envisioned and developed as a public-private partnership. Its implementation – including action planning, next steps, and policy changes - will depend on the participation and contributions of a broad group of committed partners. Given the current budget climate and in the spirit of SSB 6124, this workgroup will seek ongoing collaboration between the public and private sector to work towards the goals, strategies and recommendations.

A CALL TO ACTION

The ADWG assumes that changes can be made within or built upon the existing systems of care and services, yet also acknowledges the need for new actions and accountability. The group recognizes that the strategies and recommendations in this plan cannot be accomplished by any single organization. They cannot be accomplished by state government alone.

Some of the recommendations can be accomplished within existing resources, some through heightened collaborative work of partners, and others will take increased staff resources and funding to be fully realized. ALL will take sustained commitment, focus and coordination.

The ADWG issues a call to action:

- To establish a next generation Alzheimer's/Dementia Advisory Group to provide guidance and oversight to state plan implementation
- To collectively pursue the proposed goals, strategies and recommendations
- To engage and sustain commitment from a network of public and private partners
- To integrate activities into broader initiatives that are addressing improved health and quality of life such as Healthier Washington, Medicaid Transformation Waiver, and the Bree Collaborative End of Life Care Recommendations
- To identify opportunities to improve our state's response to dementia

GROUP RESPONSIBLE FOR IMPLEMENTATION OF THE ALZHEIMER'S DISEASE (AD) PLAN

To facilitate and monitor progress on the recommendations put forth, the ADWG proposes establishing a second generation Alzheimer's Disease (AD)/Dementia Action Advisory Group.

Responsibilities of the AD/Dementia Action Advisory Group

This group would monitor progress on the state plan recommendations and legislative actions, provide a coordinating point for implementation activities, develop action steps for recommendations that do not require legislative action, facilitate dialogue with leaders and organizations in disproportionately affected groups, prepare a periodic progress report, and inform partners as new opportunities and knowledge emerge.

Participation

The AD/Dementia Action Advisory Group to be convened initially by DSHS, in collaboration with the Steering/Executive Team, with membership to include individuals with dementia, family caregivers, legislators, representatives of the Alzheimer's Association, Alzheimer Society of Washington, ElderCare Alliance, W4A, AARP, tribal and ethnic communities, long-term care providers, health systems and medical association representatives, universities, and key state agencies including DSHS, DOH, HCA, Department of Veterans Affairs, and the Governor's Office.

AD Plan Steering/Executive Team

To include DSHS, DOH, HCA, Alzheimer's Association, ElderCare Alliance, and the Governor's Office. This Steering/Executive Team will include a link with the Joint Executive Committee on Aging & Disability, and with the Chairpersons of any subcommittees developed within the AD/Dementia Action Advisory Group.

Timeline and Next Steps

In recognition of the broad and complex nature of this Plan and the need to collaborate among many partners, the ADWG is suggesting a phased approach to implementation; the group has identified suggested timeframes to initiate work for each recommendation. Short-term would be within 2 years, mid-term within 3-4 years, and long-term in 5 years or beyond.

The identified timeframes are estimates. It is possible that there may be instances where some work may need to be deferred depending upon the availability of staff and budget resources. Conversely, preliminary work might start earlier on some recommendations.

In early 2016, the Governor and partners have agreed to convene the next generation AD/Dementia Action Advisory Group to develop a work plan for implementation considering these suggestions and available resources, determining when, and by whom each recommendation will be acted upon.

ACKNOWLEDGEMENTS

DSHS is indebted to the ADWG members – consumers and representatives of public agencies and private organizations - who thoughtfully worked to craft goals, strategies and recommendations to address Alzheimer’s and other dementias in Washington State. The panel members strove to identify recommendations that will create a sustainable, long-term plan to benefit residents from all areas of our state. They devoted many precious hours out of their busy schedules to do this work. We are deeply grateful to each of them.

Thousands of people filled out a survey, attended a public session, showed up at an ADWG session, and/or talked to a panel member about their experiences, needs, successes, challenges, hopes and fears surrounding dementia. The panel members reviewed every comment, and those contributions helped shape our state plan. We are thankful for the people of Washington State who took the time to contribute their thoughts.

Many staff contributed to this important work in many ways. They developed requested educational sessions, recruited speakers, organized subcommittee meetings, tracked the work of the ADWG, provided draft after draft of the goals, strategies and recommendations, wrote large sections of the plan and helped research hundreds of questions posed by the ADWG members and the public. The State of Washington sincerely appreciates their work and contributions.

While no funding was allotted for plan development, the cost of convening, supporting and facilitating the work, and preparing the report was made possible through funding from Older Americans Act administrative funds. The Alzheimer’s Association also generously provided additional staff and meeting supports.

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HOST SITES FOR COMMUNITY MEETINGS

**Aging and Long-Term Care of Eastern
Washington**

Spokane, Washington

The Harman Center

Yakima, Washington

Indian Policy Advisory Committee (IPAC)

Aging, Developmental Disability and

Behavioral Health Subcommittee

Olympia, Washington

North Seattle College

Seattle, Washington

Panorama City

Lacey, Washington

Shipley Center

Sequim, Washington

APPENDIX A: EXISTING RESOURCES AND CAPACITY

TYPE, COST AND AVAILABILITY OF SERVICES

Washington State's Aging and Long-Term Support Administration (AL TSA), works with thirteen Area Agencies on Aging (AAAs) who are responsible for planning, coordinating and advocating for the development of a comprehensive service delivery system at local levels to meet the needs of older adults in their planning and service areas.

At present, neither AL TSA nor the AAAs have a way to consistently quantify available services across the state for people with dementia. However, a new AAA information system is just getting underway that will manage both client information and incorporate a statewide resource directory. Once further developed, this system known as "GetCare" will allow the public and professionals to identify the availability of specific services by geographic area.

AL TSA develops a State Plan on Aging every four years. In developing its plan for 2014-2018 a statewide survey was implemented to inform planning. In regards to dementia, respondents in this survey who either had, knew or cared for a person with dementia were asked to identify the services they valued the most. Among the 1,256 people who answered this question, responses were: (1) In-home personal care (2) family caregiver supports, such as consultation, counseling, support groups (3) respite care/companion services (4) housework and errands (5) adult day centers (6) assisted living with specialized care units.⁶⁴

In addition, an open-ended question was included asking "if Washington State could improve services for people with memory loss/Alzheimer's/dementia, what would be the first step to do so?" For the 675 people who answered this question, the most common theme of these responses related to expanding education and training – for the public, family caregivers and professionals. This was true for 35% of clients/family respondents; 46% for service professional respondents). The next most common themes were for "family caregiver supports", "cost, affordability, funding, and subsidy issues".

Similar themes emerged in the public survey implemented by the Alzheimer's Disease Working Group as a part of this process (December 2014), the 2,260 respondents were asked to select five critical issues for Washington State. Four of the top five critical issues related to the availability/capacity and costs of home and community based supports. Responses were: (1) Increasing home care supports (2) Family caregiver education & support (3) Financial help with care costs, and (4) Increasing residential services.

The following section offers a brief summary of key services for people with Alzheimer's and other dementias available in the private pay market and through publicly-funded systems.

Alzheimer's and Dementia Specific Information and Support

Persons with dementia and their caregivers in Washington State can access information and supportive services through private organizations such as the Alzheimer's Association or the Alzheimer Society of Washington. The **Alzheimer Society of Washington** is a non-profit grassroots organization, providing advocacy, care and support to those with dementia and their families in Whatcom County, including programs for people with early stage memory loss, caregiver & care partner support groups, caregiver support groups, Find Me Safe - Project Lifesaver (an electronic technology program (bracelet) to locate those who wander or who may become lost in partnership with the Whatcom County Sheriff's office) and memory awareness screenings.

The **Alzheimer's Association** is the world's leading voluntary health organization in Alzheimer's care, support, and research. The Association's **Washington State Chapter** serves all of Washington as well as Northern Idaho from offices in Seattle and Spokane. Specific services provided include:

- Toll-free Helpline (1-800-272-3900) - information, assistance, referrals, and answers to questions about Alzheimer's disease and related disorders 24 hours a day, 7 days a week
- Web-based Resources (www.alzwa.org) – information about dementia, links to local services and supports, and peer-to-peer connections
- Support Groups - available in community settings or via telephone at a variety of times of the day and week for spouses, adult children, family caregivers, and people with dementia
- Early Stage Programming – information, support groups, and social engagement for individuals in the early stage of the disease and their caregivers
- Care Consultation - individualized assistance, problem solving, care planning and coordination for persons with memory loss and their families
- Education – evidence-based, dementia-specific education and training for family and professional caregivers
- MedicAlert + Safe Return - nationwide program that provides assistance when someone with Alzheimer's or a related dementia wanders and becomes lost.
- Advocacy – grass roots efforts to engage elected officials at all levels of government to improve and increase dementia care and services, access to community-based care, quality care in residential settings, and funding for research.

In-Home and Residential Services Available for Private Pay Consumers

Services such as in-home care, respite, community residential and nursing facility care are available for citizens to purchase privately. Among these are in-home care, adult day services, adult family home, assisted living and nursing home care. Rates and availability of such services vary by community.

Estimated statewide median rates for the following services follow in the table below:

Table 2. Estimated private pay rates for long-term care settings.

Service	Estimated Private Pay Rates
Home care services	\$24 per hour
Adult day health care	\$68 per day
Assisted living facility care	\$4625/month (single room) \$55,500/year
Adult family home care*	\$137 per day \$50,005/year
Nursing home care	\$266 per day (semi-private) \$96,933/year

**DSHS Management Services estimates \$137/day for Adult family home care; remainder of rates are from Median Cost Estimates for private pay from Genworth.⁶⁵*

Because Alzheimer's disease and other dementias span the course of many years and care needs increase over that time, a significant percentage of individuals and families eventually turn to long-term services and supports (LTSS) provided through state and federal public funding, such as Medicaid and Older Americans Act. These services are covered in following section.

HOME AND COMMUNITY-BASED RESOURCES

Washington State's Department of Social and Health Services, Aging and Long-Term Support Administration has developed a statewide network of home and community-based services that are available to help people stay healthy and age-in-place in their homes and communities. Resources support adults living at home who need information and services to assist with chronic care needs or disabilities and adults who are no longer able to live at home but want to live in a residential setting. Washington ranks second in the nation for providing quality long-term supports.⁶⁶

Adults with memory issues and/or diagnosed dementia are served in numerous programs and different of settings of the long-term services and supports (LTSS) system. This has prompted, over time, the development of policies that are inclusive of people

with dementia (e.g., Medicaid Waiver eligibility incorporates cognitive impairment) and some dementia-specific services targeted to the particular needs of the population (e.g., Memory Care & Wellness Services, STAR-C, and the Specialized Dementia Care Program in Assisted Living Facilities). Other services, while not dementia-specific, assist a substantial percentage of people living with memory loss/dementia (e.g., Information & Assistance/Aging & Disability Resource Centers, case management, personal care providers).

Included below is a sample of the publicly-funded long-term services and supports of particular relevance to people with Alzheimer's or related dementias and/or their family caregivers.

Adult Protective Services (APS)

Individuals with dementia or other cognitive impairments are thought to be at greater risk of abuse and neglect than those of the general older adult population. APS receives and investigates allegations of abuse (physical, mental, sexual, and exploitation), abandonment, neglect, self-neglect, and financial exploitation of vulnerable adults living in their own homes and in facilities where there is an allegation of mistreatment by someone outside of the facility. The target population are adults 60+ who cannot care for themselves; or adults 18+ that have a legal guardian; have a documented developmental disability; receive services from a DSHS-contracted individual provider; receive in-home services through a licensed health, hospice or home care agency; or have a personal care aide who performs care under his/her direction for compensation, per 74.39.050 RCW.

Community Living Connections (CLC)

CLC includes Information & Assistance (I & A) which is available for older adults, caregivers, families and professionals assisting or advocating on behalf of older adults. CLC, known nationally as Aging and Disability Resource Centers (ADRCs), are designed to broaden services to individuals of all ages with long-term service and support needs. These services are integrated points of entry into the long-term and home or community-based service and support system and are designed to address the frustration many consumers and their families experience when they need to obtain information and access to services.

I & A is available statewide through 13 Area Agencies on Aging. Aging and Disability Resource Centers are operating in four of the Area Agencies on Aging, and expansion to additional areas is based upon additional funding.

Family Caregiver Support Program

The Family Caregiver Support Program (FCSP) serves unpaid family caregivers of adults (18+) with functional disabilities. The FCSP serves a significant population of families living with dementia. Statistics reveal around 53% of care receivers have either a probable or firm diagnosis of Alzheimer's disease/dementia; another 32% are suspected to have memory or cognitive problems (2015).

The Family Caregiver Support Program (FCSP) offers an evidence-based caregiver assessment/consultation and care planning process (TCARE®) in addition to support and services that includes: help in finding and accessing local resources and services; caregiver support groups and counseling; training on specific caregiving topics (including Alzheimer's disease/dementia); education (e.g., Powerful Tools for Caregivers); access to supplies/equipment; and support/practical information and caregiving suggestions. In addition, respite care is available based upon a sliding fee scale.

The Family Caregiver Support Program is available statewide.

Adult Day Service Programs

“Adult day care” is a supervised daytime program providing core services for adults with conditions that do not require the intervention or services of a registered nurse or licensed rehabilitative therapist. “Adult day health” provides supervision along with skilled nursing and/or rehabilitative therapy services. Both these programs may serve people with dementia where they are available. Based on DSHS data and information from Leading Age, there are currently around 40 adult day centers operating statewide, with 26 of them contracted for publicly supported service provision.

Memory Care & Wellness Services (MCWS) is a dementia-specific, evidence-informed, adult day program for individuals and family caregivers. The program offers a blend of health, social and family caregiver supports and integrates a structured, specialized exercise program called *EnhanceMobility*. A University of Washington study of MCWS showed that for participants in the program with dementia, quality of life improved and the frequency of behavior problems decreased. For family caregivers, distress over behavior problems decreased for caregivers in the program, while distress increased in the comparison group of caregivers. Depressive symptoms, stress and burden also decreased for caregivers participating in the Memory Care & Wellness Services program.⁶⁷

Memory Care & Wellness Service programs are available at six adult day centers within three Area Agencies on Aging: King County and Northwest Washington are supported through limited funding from the Family Caregiver Support Program; Pierce County's grant ended in 2014 and needs additional funding to sustain the program.

STAR-C Dementia Consultation (focus on Behavioral Problem-Solving)

STAR-C is an evidence-based dementia consultation program for caregivers. Trained, certified consultants provide in-home education and consultation during four home visits and offer additional phone support over a six-week period. Developed at the University of Washington, this in-home education/consultation program has shown to improve care receiver quality of life, reduce the frequency of problem behaviors, and lower caregiving depression, burden, and distress over care receiver behavior changes.⁶⁸ The service is targeted to unpaid family caregivers who care for a person with Alzheimer's disease or other dementia, and is funded through the Family Caregiver Support Program (FCSP).

STAR-C Dementia Consultation is available on a limited basis in five Area Agencies on Aging. Training and certification of consultants has been supported through Older Americans Act and federal grant funding as available, while limited FCSP funds are allotted for direct services. Further expansion would require additional infrastructure funding.

In-Home Care Services

In-home care services are designed for individuals who, because of their health concerns, need care supports to remain in the home. Some families pay privately for such care with an individual or through home care agencies. In-home care service agencies are licensed to administer or provide home health, home care, hospice or hospice care center services directly or through contractual arrangements.

“Home care” or non-medical services may include personal care such as assistance with dressing, feeding and personal hygiene to facilitate self-care; assistance with household tasks, such as housekeeping, shopping, meal planning and preparation, and transportation; respite care assistance and support provided to the family; or other nonmedical tasks, or delegate tasks of nursing. “Home health services” may include nursing services, home health aide services, physical-occupational-speech therapy services, nutritional services, medical social services, home medical supplies or equipment services, and professional medical equipment assessment services. “In-home hospice” services may include symptom and pain management provided to a terminally ill patient, and emotional, spiritual and bereavement support for the patient and family.

Financial assistance for personal care in the home may be available for individuals who meet the financial and functional eligibility for the Community Options Program Entry Services (COPES) waiver. Cognitive impairment is a consideration in eligibility and in the algorithm that generates the level of service authorization/rates for long-term services and supports.

In 2015 there were 438 licensed in-home service agencies available across the state. Of these, 47 were contracted to provide services to Medicaid eligible clients.

It is estimated that around 10% of residents using in-home services through Medicaid have a diagnosis of Alzheimer’s disease or other dementia.⁶⁹

ASSISTED LIVING OPTIONS

Assisted Living Facilities

Assisted Living Facilities (ALFs), formerly called “boarding homes”, are community-based residential settings licensed to provide care for seven or more residents, with the express purpose of providing housing, basic services (assistance with personal care, activities of daily living and room and board) and the general responsibility for safety and well-being of the resident. See Chapter 388-78A WAC. ALFs are available to individuals requiring support and supervision. Some ALFs provide intermittent nursing

services or may serve residents with mental health problems or dementia. The majority are privately owned businesses. Most residents pay for their care privately.

In 2015, there are 541 licensed Assisted Living Facilities in Washington State.

It is estimated that around 34% of residents in ALFs on Medicaid have Alzheimer's disease or other dementia.⁶⁹

Specialized Dementia Care Settings within ALFs

There are currently no standards or definition in the private pay market of what "memory care" or "specialized dementia care" units are or must provide. And the number of such specialized units in ALFs across the state is not known.

For publicly-funded residents, though, the State has a Specialized Dementia Care Program (SDCP) contract to guide practices.

The SDCP serves individuals with Alzheimer's disease or other dementia who are eligible for both the Medicaid/COPES waiver and the SDCP. SDCP services are provided within facilities that are either dedicated solely to the care of persons with dementia, or providing such care in a separate unit dedicated solely to the care of persons with dementia within larger facilities. Pilot project findings demonstrated that participation in the SDCP resulted in significant delay in nursing home placement. Standards of Care were adopted and placed into WAC 388-110-220(3) in 2003. SDCP eligibility can be found in **WAC 388-106-0033**.

In 2015, the Specialized Dementia Care Program was available in all DSHS regions through contracts with 61 facilities. The SDCP served 932 individuals during 2014.

Adult Family Homes

Adult Family Homes (AFHs) are another community residential care option in Washington. An AFH is a residential home in which a person or persons provide personal care, special care and room and board for two to six residents who are not related by blood or marriage to the persons providing the services. The homes are private businesses and provide the residents with a room, meals, laundry, supervision, assistance with activities of daily living, and personal care. Some provide nursing services. Residents can pay privately or be funded through DSHS. Adult Family Homes may be designated as a specialty home (on their license) for dementia if they meet all certification and training requirements (see Training Requirements below). See **Chapter 388-76 WAC** for more on adult family home licensing requirements.

In 2015, there were 2,767 licensed AFHs (2,755 of which have met the requirements to be designated as dementia specialty homes).

Around 43% of AFH clients on Medicaid have a diagnosis of AD or other dementia identified in the state's functional assessment system.⁶⁹

LONG-TERM DEMENTIA UNITS

Skilled Nursing Facilities (SNFs) provide care for individuals whose conditions are complex and/or medically unstable and who require frequent medical or nursing interventions. These facilities have nursing services 24-hours a day. They provide at least daily nursing supervision to residents needing health services and restorative or maintenance assistance with medications, eating, dressing, walking and other personal care needs.

In 2015, there were 229 Skilled Nursing Facilities in Washington State (2015). Around 41% of SNF residents in SNFs have Alzheimer's or other dementia.

Thirty-nine (39) of the SNFs are indicated to have specialized dementia care units. SNFs that began operating a dementia care unit at any time after November 13, 1989, must meet all physical facility requirements outlined in WAC [388-97-2820](#) through [388-97-2920](#). In addition, they must meet for program requirements for dementia care outlined in WAC [388-97-1040](#).

DEMENTIA-SPECIFIC TRAINING REQUIREMENTS

The State of Washington has been working towards strong training requirements related to dementia care in varied settings and provider types.

Licensed Certified Nursing Staff

Licensed certified nursing staff, including Registered Nurses (RNs), Licensed Practical Nursing (LPNs), and Nursing Assistants-Certified (NACs), have standards of practice and competencies expectations to include maintaining, updating and demonstrating sufficient knowledge, skills, and judgement to practice safely and ethically in their designated role. RNs and LPNs participate in on-going continuing education to augment professional knowledge, skill set and judgement. The ongoing trainings may be obtained through mentorship programs, clinical presentations, certification classes, and specialty certification classes. It is expected each discipline must have the optimal knowledge base to work within the specialty needs of their resident population - including understanding and meeting the needs and behaviors of individuals with cognitive impairment including Alzheimer's disease, dementia, delirium, developmental disabilities, mental illnesses, and other conditions.

To be certified to practice in Washington as a Nursing Assistant-Certified (NAC), regulations mandate that nursing assistants must be able to identify the psychosocial characteristics of patients with dementia and Alzheimer's disease. In addition, the regulations specify the areas of competency that are considered standards of practice for nursing assistants. A nursing assistant must demonstrate competency in the care of residents with Alzheimer's disease and dementia in the following areas: (a) uses techniques for addressing the unique needs and behaviors of individuals with cognitive

impairment including Alzheimer's disease, dementia, delirium, developmental disabilities, mental illnesses, and other conditions; (b) communicates with cognitively impaired clients or residents in a manner appropriate to their needs; (c) demonstrates sensitivity to the behavior of cognitively impaired clients or residents; and (d) appropriately responds to the behavior of cognitively impaired clients or residents.

Nursing Homes

Each nursing home must provide residents who have dementia, an environment designed to attain or maintain the highest level of functioning and wellbeing possible. All staff who have direct resident contact, must be trained in special needs and care approaches applicable to residents with dementia. The training must be ongoing and consistent with the requirements of the nursing home staff development program. And staff development programs, under the direction of RN or LPN, must include in-service education to maintain a knowledge base specific to the resident population, including dementia care as applicable.

Long-Term Care Workers

Initiative 1163, passed in 2011, expanded training requirements for long-term care workers who provide personal care services to older adults or those with disabilities. Long-term care services are provided by employees of licensed home care agencies, Adult Family Homes, Assisted Living Facilities and by Individual Providers. Home care agency workers provide care for clients in their own homes. Individual Providers are contracted with DSHS to provide care to Medicaid-eligible older adults in their own homes. Long-term care workers who are not an RN, LPN, Advanced Registered Nurse Practitioner or Nursing Assistant-Certified are required to complete 5 hours of orientation and safety training before providing paid personal care – and 70 hours of basic training on topics, including dementia, within the first 120 days. They must apply to the Department of Health (DOH) for a Home Care Aide credential and they have up to 200 days (or 260 days if they are non-English speakers) from their date of hire for DOH to issue them this credential which includes passing a written and skills demonstration certification exam.

The Department of Social and Health Services, within one of its functions, licenses and monitors the state's residential care options, including Assisted Living Facilities (ALF) and Adult Family Homes (AFH). Within that network, three care specialties currently exist which require long-term caregivers to receive specialty training, one of which is related to dementia. These three specialties have established training curricula and requirements that are detailed in the Washington Administrative Code (WAC), Chapter 388-112—Residential Long-Term Care Services.

The current training curriculum for dementia in AFH and ALF settings includes the following modules: Introduction to Dementia, Communicating with People Who Have Dementia, Creative Approaches to Challenging Behaviors, Helping with Activities of Daily Living (ADLs), Hallucinations and Delusions, Sexuality and Dementia, Medications and Dementia, and Setting the Tone.

In 2012, the Adult Family Home Quality Assurance Panel Report outlined concerns around training, indicating that specialty training does not result in an expert level of “specialization” of service, contrary to what the public may assume is implied by the term “specialty.” The dementia training for caregivers is 6 hours long and not sufficient. Recommendation 4.2 #5 within the report states:

DSHS should expand, standardize, and improve instruction of specialty trainings, including the dementia training. Specialty training courses on dementia, mental health, and developmental disabilities must be re-designed to expand on content and current best practice. Initiative 1163 expanded basic training but did not revise the requirements for specialty training. The specialty courses must be standardized in both curricula and instruction techniques, and be accompanied by tools used to effectively and fairly evaluate successful student completion. The course design and development must include participation by experts in the given specialty, as well as providers and consumers.⁷⁰

Beginning in January of 2014, DSHS retained the services of Coraggio Group to assist in implementing sections of SSB 5630 that enact recommendations of the Adult Family Home Quality Assurance Panel and relate to improvement of and expansion of specialty trainings for Adult Family Homes.

After gathering input from over 400 stakeholders on current trainings and requirements, identifying opportunities to improve the trainings, identifying needs for additional specialty trainings, and opportunities to revise relevant portions of the WAC – Coraggio Group investigated content, instructional quality and program design to understand current research in care and adult education as well as trends among other states and international care programs. The effort also included visits to Adult Family Home facilities and interviews with caregivers and providers. Based on this combination of stakeholder input and research, Coraggio Group created recommendations which can be found on the DSHS [website](#).

While DSHS supports many of the recommendations outlined in the reports, several of the recommendations are contingent upon future funding appropriations.

QUALITY CARE MEASURES FOR ASSISTED LIVING FACILITIES, ADULT FAMILY HOMES AND NURSING HOMES

The State has a number of initiatives in quality assurance and improvement that support clients, including those with dementia, as described below.

Quality Assurance

The State and federal Centers for Medicare and Medicaid Services (CMS) regulate nursing homes. CMS conducts tandem inspections with the State and conducts its own surveys to determine the validity of State assessments.

The State (Residential Care Services) conducts unannounced annual inspections/surveys to ensure facilities meet the minimum care and safety requirements specified in law and rule, conducts complaint investigations regarding provider practice concerns, and in response to findings, may cite a facility and may also impose additional enforcement actions including civil fines, license revocation or decertification, and referral of criminal allegations to law enforcement.

Washington's residential settings, including Assisted Living Facilities (ALF) and Adult Family Homes (AFH), are also inspected on a regular basis (at least every eighteen months, with annual average of fifteen months) to ensure they meet the minimum care and safety requirements specified in law and rule. However, the department may delay an inspection to twenty-four months if the ALF or AFH has had three consecutive inspections with no written notice of violations and has received no written notice of violations resulting from complaint investigation during that same time period. The department may at any time make an unannounced inspection of a licensed ALF or AFH to assure that the licensee is in compliance with respective rules and regulations.

Compliance surveys/inspections are one of numerous quality assurance activities that occur within the licensed or certified homes/facilities.

- RCS has complaint investigators who investigate complaints in the licensed or certified homes/facilities related to provider practice and services concerns. These complaints are referred to the RCS investigators by the DSHS Complaint Resolution Unit (CRU).
- The CRU receives and prioritizes complaints regarding provider practice, including suspected abuse or neglect in long-term care settings that have been called into the CRU Hotline (1-800-562-6078). The CRU hotline is available 24 hours a day, seven days a week for the public and licensed or certified homes/facilities staff. Licensed or certified homes/facilities staff are mandated reporters and are required to report specific types of incidence to the CRU hotline. Depending on the nature and severity of the reported issues, calls may also be referred to local law enforcement, licensing boards, Medicaid Fraud, county prosecutors and sheriffs, and Adult Protective Services.
- If, after an annual survey/inspection or a complaint investigation, a violation of the regulations is found a statement of deficiency is written and the licensed or certified home/facility is required to correct the problem(s) that is identified in the deficiency report. Depending on the severity of the deficiency and the number of residents impacted by the deficiency, RCS may also impose additional enforcement action that range from civil fines to license revocation or decertification and referral of criminal allegations to law enforcement. Follow-up visits are made by RCS investigators to ensure regulation violations are corrected and do not continue.

Dementia Specialty Training, outlined in Washington law (RCW 18.20.270), is required of administrators, or designees, and caregiving staff for Assisted Living Facilities and Adult

Family Homes that serve residents with dementia. This training was discussed in the section above.

Quality Care Measures

In terms of quality care “measures”, CMS specifies that States in administering Medicaid services meet their quality expectations for administrative oversight, financial accountability, level of care, service plans, qualified providers, and participant health and welfare. Each state develops performance measures to support each expectation. The quality assurance monitoring questions feed into related performance measures for individual providers, agency providers, Adult Family Homes and Assisted Living Facilities.

These measures focus on the system/processes to ensure that minimum requirements are met. In 2015, these include measures related, but not limited to: the timeliness of facility inspections a complaint investigations, provider qualifications being met related to background checks and training, service plans addressing participants assessed needs and personal goals, participants having an active role in developing their care plans, and ensuring that bed rails are not used as a restraint.

Care Quality Information Available to Consumers

- *Nursing Home Compare*, is a website operated by CMS that collects and shares specific data related to health inspections and quality measures for every Medicare and Medicaid-certified nursing home in the country. The data and a 5-star rating system is available to assist consumers in making choices based on specific measures of quality.
- The *Adult Family Home Locator* and *Assisted Living Facility Locator* are tools for families seeking information about community residential options by geographic area. On these webpages, as a part of their listing, consumers can also find information on deficiencies, enforcement actions and civil fines imposed.

GERIATRIC PSYCHIATRIC UNITS

For individuals with dementia who exhibit severe, disruptive or unsafe behaviors, hospital units skilled in evaluation, treatment and care coordination can become necessary in the course of the illness. There is no coordinating or regulatory body that sets expectations for services that should be available in communities or expectations for the quality of these services. Ideally, individuals can be admitted to geriatric psychiatric (geropsych) units in community based hospitals for short-term evaluation and treatment but these are few and beds are limited.

The following is a summary of hospitals that accept and specialize in caring for patients presenting with geriatric psychiatric behavioral challenges in Washington State. Geriatric Psychiatric beds and services are not specifically licensed for in Washington State. These services are provided under a psychiatric or acute hospital license.

- Northwest Hospital Geropsychiatric Center (27 beds accepting both voluntary and involuntary admissions), North Seattle
- Cascade Behavioral Hospital (10 beds accepting voluntary admissions), between Seattle and Tacoma
- Multicare Auburn Regional Medical Center (up to 25 beds accepting voluntary admissions), South Seattle

The Department of Health's Office of Community Health Systems reports there are no geropsych inpatient beds in Washington's Critical Access Hospitals (CAHs) and there is no other entity that can report services in other rural hospitals in the state so this information is difficult to obtain. Another contributing factor is simply the overall number of psychiatric beds in Washington State. In 2009, Washington State ranked 47th in the US for the number of community psychiatric beds per 100,000 population.⁷¹

If beds are not available, individuals are frequently transferred to emergency departments and end up being 'held' waiting for geropsych or regular psychiatric hospital beds, or even held on medical floors with continuous supervision, long after medical conditions have resolved. Geropsych units also report that limited long-term care options can increase lengths of stay, further complicating the issues. In 2008, the Washington State Hospital Association reported that United General Hospital in Sedro Woolley was closing its Senior Behavioral Health Center, a ten bed inpatient psychiatric unit for geriatric patients, because of a continued decline in payment *and* the increasing length of stay due to the inability to transfer to facilities with a clinically appropriate, less acute level of care.

If an individual's behavior has reached a certain threshold so that they meet the criteria for involuntary treatment under the state's civil commitment law (WAC 71.05), he or she may be detained to one of the state psychiatric hospitals. At that time, patients are treated primarily for psychiatric symptoms, despite the fact that most individuals with dementia have co-occurring medical issues and behavior issues. The units in which they are treated are not designed for dementia care and can sometimes exacerbate unwanted behaviors, such as aggression, making placement even more challenging. Medical conditions can either progress or are difficult to resolve in a timely manner. This in turn can delay, or in some instances, even prevent discharge to appropriate community based housing and treatment.

The lack of geropsych units/beds available to evaluate and treat severe behaviors may also be a contributing factor for the significant use of antipsychotics in community settings. The United States Government Accountability Office (GAO)'s 2015 analysis found that about one-third of older adults with dementia who spent more than 100 days in a nursing home in 2012 were prescribed an antipsychotic, and about 14% living outside a nursing home, despite the FDA's boxed warning that these drugs may cause an increased risk of death when used by older adults with dementia and the drugs are not approved for this use (US Government Accountability Office, 2015). In the state of Washington, Qualis Health reports that the Q4 2014 antipsychotic use in nursing homes

was 17.6%, ranked 21 (lower is better) in the U.S. but there is a national goal of reducing by 15%. The GAO has recommended to the HHS that efforts be expanded to other settings as well.

Specialized geropsychiatric units are limited to the Seattle area. Additional units and alternatives to inpatient geropsychiatry need to be available throughout the state for assessment of individuals exhibiting severe behaviors, which will require further investigation and development.

In addition, emergency crisis services provided by skilled individuals are critical in communities to help deescalate situations or to appropriately support the individual and caregiver as the person is removed from home or a facility. These types of crisis services are also limited. One such program exists in King County.

- The Geriatric Regional Assessment Team (GRAT) provides crisis intervention services in King County evaluating whether individuals need to be hospitalized. They work with designated mental health professionals who link individuals to community resources. As part of their program GRAT provides training for first responders and the criminal justice system. GRAT is funded through 1% of a 1 cent 'min' tax and federal grants and is part of the mental health support program in King County.

As mentioned, when individuals with dementia and behavior challenges are admitted to the psychiatric hospitals, they need to be transitioned back into the community. The following are two programs offered under Medicaid contract for eligible clients through Aging and Long-Term Support Administration.

- Expanded Community Services (ECS) are designed for Medicaid clients with exceptional care needs due to behavioral or mental health issues and successful placement is not possible because of significant behavioral challenges. DSHS contracts with, and offers an enhanced rate to skilled nursing and residential providers for this service.
- An Enhanced Service Facility designation has recently been developed to offer behavioral supports and other care in specialized residential facilities and are designed for individuals with mental health and/or chemical dependency disorders; organic or traumatic brain injuries; and/or cognitive/developmental impairments who are relocating from a psychiatric hospital when acute inpatient treatment is no longer medically necessary or the individual cannot benefit from active treatment. To be eligible, clients must meet Nursing Facility Level of Care and Enhanced Service Facility criteria. This new Medicaid program (no contracted facilities as of July 2015) will be funded through a 1915(C) waiver and the budget assumes 42 beds will be eventually be filled.

STATE SUPPORT OF ALZHEIMER'S RESEARCH

The University of Washington is home to the Alzheimer's Disease Research Center (UW ADRC). In existence since 1985, the UW ADRC is an active collaborator in multiple national initiatives that harness the combined power of the thirty-one Alzheimer's Disease Centers nationally. The UW ADRC is focused on precision medicine for Alzheimer's disease by advancing research in genetic risk, developing neuroimaging and biomarkers for pre-clinical detection, and discovering novel therapeutics tailored to an individual's molecular drivers of disease. More information can be found on their [website](#).

To date, the UW ADRC has had the following accomplishments in three core areas of focus:

Research

- Discovered new genes for early onset Alzheimer's disease and frontotemporal dementia
- Made major contributions to determining mechanisms of disease, and for risk and protective factors for Alzheimer's disease
- Pioneered investigation of biomarkers of Alzheimer's disease and showed that they are present up to two decades before symptoms of Alzheimer's begin
- Is developing a novel treatment for the disruptive agitation in Alzheimer's disease that is a major cause of caregiver distress and nursing home placement
- Published over 1000 peer reviewed scientific papers

Clinical

- Currently enrolls over 400 volunteers with Alzheimer's disease, related dementias, and cognitively normal people in clinical research
- Partners with other research teams across the world to accelerate discovery in genetics, body fluid and neuroimaging biomarkers, and treatment trials
- Conducts clinical trials for treatment of Alzheimer's disease, for slowing progression of the disease, and for Alzheimer's prevention


Training and Outreach

- Reaches out to underserved groups in the Pacific Northwest, both African Americans and Native Americans, to provide opportunities to volunteer for research and to advance knowledge about Alzheimer's in these diverse groups
- Trained hundreds of students, postdoctoral fellows, clinical fellows, and junior faculty to ensure that our successes are long lasting
- Presented over 2000 community education and outreach events across the Pacific Northwest
- Works to effectively inform patients, families, and health care providers of progress in Alzheimer's disease

Twenty-three faculty and forty-three non-faculty are engaged with the UW ADRC. The annual budget for the UW ADRC is approximately \$3 million, which includes both direct and indirect funds. The State of Washington provides funding in the form of tenure line partial salary for some faculty who are members of UW ADRC but who are not designated for ADRC activities. The National Institute of Health provides the bulk of the research funding, totaling nearly \$70 million since 1985. In addition to grant funds, the UW ADRC has received approximately \$6.5 million in donations, the vast amount of which was received recently from the Ellison Foundation to advance precision medicine for Alzheimer's disease.

Note to reader: If you have downloaded the core report only, Appendices B – H can be found on the Alzheimer's Disease Working Group's website at:

www.dshs.wa.gov/altsa/stakeholders/alzheimers-state-plan



Preparing Washington for the Impacts of Alzheimer's Disease and Other Dementias

For more information, please visit:
<https://www.dshs.wa.gov/altsa/stakeholders/alzheimers-state-plan>

