

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

Appendices B-H
January 1, 2016



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

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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

APPENDIX B: LEGISLATIVE CHARGE

CERTIFICATION OF ENROLLMENT
SUBSTITUTE SENATE BILL 6124
Chapter 89, Laws of 2014 63rd Legislature
2014 Regular Session

STATE ALZHEIMER'S PLAN
EFFECTIVE DATE: 06/12/14

Passed by the Senate February
14, 2014 YEAS 47 NAYS 1

BRAD OWEN

President of the Senate

Passed by the House March
6, 2014 YEAS 90 NAYS 6

FRANK CHOPP

**Speaker of the House of
Representatives**

Approved March 27, 2014, 10:45
a.m.

JAY INSLEE

**Governor of the State of
Washington**

CERTIFICATE

I, Hunter G. Goodman, Secretary
of the Senate of the State
of Washington, do hereby
certify that the attached is
SUBSTITUTE SENATE BILL 6124 as
passed by the Senate and the
House of Representatives on the
dates hereon set forth.

HUNTER G. GOODMAN

Secretary

FILED

March 27, 2014

**Secretary of State State of
Washington**

SUBSTITUTE SENATE BILL 6124

Passed Legislature - 2014 Regular Session
State of Washington 63rd Legislature 2014 Regular Session

By Senate Health Care (originally sponsored by Senators Keiser, Dammeier, Hargrove, Ranker, McCoy, Hasegawa, Conway, Darneille, McAuliffe, Cleveland, Billig, Rolfes, Nelson, Mullet, Fraser, Frockt, Eide, Kohl-Welles, Kline, Hobbs, Pedersen, Hatfield, Parlette, Roach, and Becker)

READ FIRST TIME 02/07/14.

AN ACT Relating to developing a state Alzheimer's plan; creating new sections; and providing an expiration date.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF WASHINGTON:

NEW SECTION. **Sec. 1.** The department of social and health services must convene an Alzheimer's disease working group to develop a state Alzheimer's plan that consists of the following members to be appointed by the department unless indicated otherwise:

- (1) At least one unpaid family caregiver of a person who has been diagnosed with Alzheimer's disease;
- (2) At least one professional caregiver of a person who has been diagnosed with Alzheimer's disease;
- (3) At least one individual provider caregiver of a person who has been diagnosed with Alzheimer's disease;
- (4) At least one person who has been diagnosed with Alzheimer's disease;
- (5) A representative of nursing homes;
- (6) A representative of assisted living facilities;
- (7) A representative of adult family homes;
- (8) A representative of home care agencies that care for people with Alzheimer's disease;
- (9) A representative of adult day services;
- (10) A health care professional who treats people with Alzheimer's disease;
- (11) A psychologist who specializes in dementia care;

- (12) A person who conducts research on Alzheimer's disease;
- (13) A representative of the Alzheimer's association;
- (14) A representative of the Alzheimer society of Washington;
- (15) The governor or the governor's designee;
- (16) The secretary of the department of social and health services or the secretary's designee;
- (17) The secretary of the department of health or the secretary's designee;
- (18) The director of the health care authority or the director's designee;
- (19) The long-term care ombuds or the ombuds' designee;
- (20) A member of the senate health care committee, appointed by the senate;
- (21) A member of the house of representatives health care and wellness committee, appointed by the house of representatives;
- (22) Five health policy advocates including representatives of the American association of retired persons, area agencies on aging, elder care alliance, and other advocates of the elderly or long-term care workers;
- (23) A representative of the University of Washington's Alzheimer's disease research center;
- (24) A member with experience in elder law or guardianship issues; and
- (25) A representative from the Washington state department of veterans affairs.

NEW SECTION. Sec. 2. The Alzheimer's disease working group established in section 1 of this act must examine the array of needs of individuals diagnosed with Alzheimer's disease, services available to meet these needs, and the capacity of the state and current providers to meet these and future needs. The working group must consider and make recommendations and findings on the following:

- (1) Trends in the state's Alzheimer's population and service needs including, but not limited to:
 - (a) The state's role in long-term care, family caregiver support, and assistance to persons with early-stage and early-onset of Alzheimer's disease;
 - (b) State policy regarding persons with Alzheimer's disease and dementia; and
 - (c) Estimates of the number of persons in the state who currently have Alzheimer's disease and the current and future impacts of this disease in Washington;
- (2) Existing resources, services, and capacity including, but not limited to:

- (a) Type, cost, and availability of dementia services;
 - (b) Dementia-specific training requirements for long-term care staff providing care to persons with Alzheimer's disease at all stages of the disease;
 - (c) Quality care measures for assisted living facilities, adult family homes, and nursing homes;
 - (d) Availability of home and community-based resources for persons with Alzheimer's disease, including respite care;
 - (e) Number and availability of long-term dementia units;
 - (f) Adequacy and appropriateness of geriatric psychiatric units for persons with behavior disorders associated with Alzheimer's disease and related dementia;
 - (g) Assisted living residential options for persons with dementia; and
 - (h) State support of Alzheimer's research through the Alzheimer's disease research center at the University of Washington; and
- (3) Needed policies or responses including, but not limited to, the promotion of early detection and diagnosis of Alzheimer's disease and dementia, the provision of coordinated services and supports to persons and families living with Alzheimer's disease or dementia disorders, the capacity to meet these needs, and strategies to address identified gaps in services.

NEW SECTION. Sec. 3. (1) The secretary of the department of social and health services or the secretary's designee must convene the first meeting and must serve as chair of the Alzheimer's disease working group. Meetings of the working group must be open to the public.

(2) The department of social and health services must submit a report providing the findings and recommendations of the Alzheimer's disease working group, including any draft legislation necessary to implement the recommendations, to the governor and the health care committees of the senate and the house of representatives by January 1, 2016.

NEW SECTION. Sec. 4. This act expires January 31, 2016. Passed by the Senate February 14, 2014. Passed by the House March 6, 2014. Approved by the Governor March 7, 2014. Filed in Office of Secretary of State March 27, 2014.

APPENDIX C: INFORMATION ABOUT ALZHEIMER’S AND DEMENTIA

10 WARNING SIGNS OF ALZHEIMER’S DISEASE

1. Memory loss that disrupts daily life

One of the most common signs of Alzheimer’s, especially in the early stages, is forgetting recently learned information. Others include forgetting important dates or events; asking for the same information over and over and increasingly needing to rely on memory aids.

2. Challenges in planning or solving problems

Some people may experience changes in their ability to develop and follow a plan or work with numbers. They may have trouble following a familiar recipe or keeping track of monthly bills. They may have difficulty concentrating and take much longer to do things than they did before.

3. Difficulty completing familiar tasks at home, at work or at leisure

People with Alzheimer’s often find it hard to complete daily tasks. Sometimes, they may have trouble driving to a familiar location, managing a budget at work or remembering the rules of a favorite game.

4. Confusion with time or place

People with Alzheimer’s can lose track of dates, seasons and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there, or they get confused about the day of the week but figure it out later.

5. Trouble understanding visual images and spatial relationships

For some people, having vision problems is a sign of Alzheimer’s. They may have difficulty reading, judging distance and determining color or contrast, which may cause problems with driving.

6. New problems with words in speaking or writing

People with Alzheimer’s may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue or they may repeat themselves. They may struggle with vocabulary, have problems finding the right word or call things by the wrong name (e.g., calling a “watch” a “hand-clock”).

7. Misplacing things and losing the ability to retrace steps

A person with Alzheimer’s disease may put things in unusual places. They may lose things and be unable to go back over their steps to find them again. Sometimes, they may accuse others of stealing. This may occur more frequently over time.

8. Decreased or poor judgment

People with Alzheimer's may experience changes in judgment or decision-making. For example, they may use poor judgment when dealing with money, giving large amounts to telemarketers. They may pay less attention to grooming or keeping themselves clean.

9. Withdrawal from work or social activities

A person with Alzheimer's may start to remove themselves from hobbies, social activities, work projects or sports. They may have trouble keeping up with a favorite sports team or remembering how to complete a favorite hobby. They may also avoid being social because of the changes they have experienced.

10. Changes in mood and personality

The mood and personalities of people with Alzheimer's can change. They can become confused, suspicious, depressed, fearful or anxious. They may be easily upset at home, at work, with friends or in places where they are out of their comfort zone.

From the Alzheimer's Association

DIFFERENT TYPES OF DEMENTIA

Dementia is a general term for loss of memory and other mental abilities severe enough to interfere with daily life. It is caused by physical changes in the brain.

Alzheimer's disease

Alzheimer's is the most common form of dementia and accounts for 60 to 80 percent of dementia cases. Early symptoms include difficulty remembering recent conversations, names or events; apathy and depression. Later symptoms include impaired communication, poor judgment, disorientation, confusion, behavior changes and difficulty speaking, swallowing and walking.

Alzheimer's is not a normal part of aging, although the greatest known risk factor is increasing age, and the majority of people with Alzheimer's are 65 and older. But Alzheimer's is not just a disease of old age. Up to 5 percent of people with the disease have early onset (also known as younger-onset) Alzheimer's disease, which often appears when someone is in their 40s or 50s.

Vascular dementia

Previously known as multi-infarct or post-stroke dementia, vascular dementia is less common as a sole cause of dementia than Alzheimer's, accounting for about 10 percent of dementia cases. Symptoms include impaired judgment or ability to make decisions, plan or organize is more likely to be the initial symptom, as opposed to the memory loss often associated with the initial symptoms of Alzheimer's.

Dementia with Lewy bodies

People with dementia with Lewy bodies often have memory loss and thinking problems common in Alzheimer's, but are more likely than people with Alzheimer's to have initial or early

symptoms such as sleep disturbances, well-formed visual hallucinations, and muscle rigidity or other parkinsonian movement features. Symptoms include memory loss and thinking problems common in Alzheimer's, but are more likely than people with Alzheimer's to have initial or early symptoms such as sleep disturbances, well-formed visual hallucinations, and muscle rigidity or other parkinsonian movement features.

Mixed dementia

In mixed dementia abnormalities linked to more than one type of dementia occur simultaneously in the brain. Recent studies suggest that mixed dementia is more common than previously thought.

Parkinson's disease

As Parkinson's disease progresses, it often results in a progressive dementia similar to dementia with Lewy bodies or Alzheimer's. **Symptoms of the disease include** problems with movement. If dementia develops, symptoms are often similar to dementia with Lewy bodies

Frontotemporal dementia

Includes dementias such as behavioral variant FTD (bvFTD), primary progressive aphasia, Pick's disease and progressive supranuclear palsy. Typical symptoms include changes in personality and behavior and difficulty with language.

Creutzfeldt-Jakob disease

CJD is the most common human form of a group of rare, fatal brain disorders affecting people and certain other mammals. Variant CJD ("mad cow disease") occurs in cattle, and has been transmitted to people under certain circumstances. Rapidly fatal disorder that impairs memory and coordination and causes behavior changes.

Normal pressure hydrocephalus

Symptoms include difficulty walking, memory loss and inability to control urination. Caused by the buildup of fluid in the brain. Can sometimes be corrected with surgical installation of a shunt in the brain to drain excess fluid

Huntington's disease

Huntington's disease is a progressive brain disorder caused by a single defective gene on chromosome 4. Symptoms include abnormal involuntary movements, a severe decline in thinking and reasoning skills, and irritability, depression and other mood changes.

Wernicke-Korsakoff syndrome

Wernicke-Korsakoff syndrome is a chronic memory disorder caused by severe deficiency of thiamine (vitamin B-1). The most common cause is alcohol misuse. Symptoms include strikingly severe memory problems while other thinking and social skills seem relatively unaffected.

From the Alzheimer's Association

APPENDIX D: WASHINGTON STATE RESOURCES AND OTHER USEFUL LINKS

WASHINGTON STATE

Alzheimer's Association Washington Chapter

www.alz.org/alzwa

The Alzheimer's Association 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 available 24/7); Web-based Resources – information about dementia, links to local services and supports, and peer-to-peer connections; Support Groups; 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; MedicAlert + Safe Return - nationwide program that provides assistance when someone with Alzheimer's or a related dementia wanders and becomes lost; and advocacy.

Seattle Office:

100 W Harrison Street
Suite N200
Seattle, WA 98119
(206) 363-5500
InquiryWa@alz.org

Spokane Office:

1403 S Grand Blvd
Suite 202-S
Spokane, WA 99203
(509) 456-0456
InquiryWa@alz.org

Alzheimer Society of Washington (Whatcom County)

www.alzsociety.org

The Alzheimer Society of Washington (360-671-3316 or 1-800-493-3959) 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.

1308 Meador Ave, Suite C1
Bellingham, WA 98229
360.671.3316
alz@alzsociety.org

Aging and Long-Term Support Administration (AL TSA), Department of Social and Health Services

www.dshs.wa.gov/altsa

Home and Community Services (HCS) provides and administers long-term care services to eligible individuals and collaborates with **Area Agencies on Aging** (AAA) offices statewide to share community service options, including supports for family caregivers. To find information in your area, **call your local HCS or AAA office.**

Residential Care Services provides licensing, certification, and regulatory oversight to long-term care facilities including: Nursing Home, Assisted Living Facilities, Adult Family Homes, Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID), Supported Living; and Enhanced Services Facilities.

Office of the Deaf and Hard of Hearing provides service to individuals who are deaf, hard of hearing, deaf-blind and speech-disabled facing communication barriers. Services includes telecommunications, reasonable accommodations and client services.

General Information: (360) 725-2300 or 1-800-422-3263

NATIONAL ORGANIZATIONS AND RESOURCES

Alzheimers.gov

www.alzheimers.gov

Alzheimer's Association, National

www.alz.org

Alzheimer's Association Research Center Trial Match

www.alz.org/research/clinical_trials/find_clinical_trials_trialmatch.asp

Alzheimer's Association 2015 Facts & Figures

www.alz.org/alzheimers_disease_Facts_and_Figures.asp

Alzheimer's Disease Education and Referral Center, National Institute on Aging,

www.nia.nih.gov/alzheimers

Alzheimer's Foundation of America

www.alzfdn.org

Alzheimer's Prevention Initiative

www.endalznw.org

Caregiver Action Network

caregiveraction.org

Centers for Disease Control: The Healthy Brain Initiative: A National Public Health Road Map to Maintaining Cognitive Health

www.cdc.gov/aging/healthybrain/roadmap.htm

Hand in Hand, a Training Series for Nursing Homes

www.cms-handinhandtoolkit.info

Healthy People 2020: Dementias

www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=7

AD: Leaders Engaged on Alzheimer's Disease

www.leadcoalition.org

Mayo Clinic Alzheimer's Disease Center

www.mayoclinic.com/health/alzheimers-disease/DS00161

Minnesota ACT on Alzheimer's website

www.actonalz.org

Namaste Care for People with Dementia

www.namastecare.com

National Alliance for Caregiving

www.caregiving.org

National Alzheimer's Project Act (NAPA) home page, and link to the National Plan to Address Alzheimer's Disease

aspe.hhs.gov/daltcp/napa/

National Institute on Aging: Caring for a Person with Alzheimer's Disease

www.nia.nih.gov/alzheimers/publication/caring-person-alzheimers-disease

National Task Group on Intellectual Disabilities and Dementia Practices

aadmd.org/ntg

Partnership for Patients

partnershipforpatients.cms.gov

INTERNATIONAL RESOURCES

Alzheimer's Disease International (World Reports)

www.alz.co.uk

International Alzheimer's Disease Research Portfolio (IADRP)

iadrp.nia.nih.gov/cadro-web/le

The Dementia Challenge (United Kingdom)
dementiachallenge.dh.gov.uk

Dementia Friendly Communities (Scotland)
www.adementiafriendlycommunity.com

Dementia Friends (United Kingdom)
www.dementiafriends.org.uk

INVENTORY OF SUPPORTS AND SERVICES IN WASHINGTON STATE FOR PEOPLE WITH ALZHEIMER'S DISEASE AND OTHER DEMENTIAS

CONTENTS

1. Background
2. Services available through the Aging & Disability Network
(Dementia-specific services are presented first; general services for this population follow in alphabetical order.)
3. Medicaid State Plan and Medicaid Waiver Service
(Dementia-specific services are presented first; general services for this population follow in alphabetical order.)
4. Long-Term Services, Support Settings and Provider Types
5. Protective Services

BACKGROUND

Individuals with Alzheimer’s disease and other dementias and their caregivers can access information and supportive services through organizations in the private sector such as the Alzheimer’s Association Washington State Chapter, the Alzheimer Society of Washington, or through home care agencies and adult day services centers. Because of the duration of illness and increasing care needs over its progression, though, many individuals with dementia eventually turn to long-term services provided by state and federal public funding such as Medicaid and Older Americans Act.

Washington State has developed a statewide network of home and community-based services – these range from information & assistance, meals or education around disease management to assistance with tasks such as bathing, dressing, ambulation, transfers, toileting, medication administration/reminders, personal hygiene, meal preparation, transportation and other personal, household or health-related tasks. These services and supports allow individuals to choose the setting and services that will best meet their needs and preferences for quality, independence and self-determination.

Over 80% of long-term services and supports are provided by unpaid family caregivers. AARP estimates that Washington State has over 850,000 unpaid family caregivers supporting their loved ones. The care they provide has an estimated economic value of \$10.6 billion, almost 5 times what the state of Washington spends annually on Medicaid funded long-term supports and services. Washington State’s state- and federally-funded Family Caregiver Support Program currently reaches 1% of unpaid family caregivers in the state.

Medicaid is the primary public payer of long-term services and supports. Medicare only pays for qualified short-term stays in nursing homes for rehabilitative services. Individuals also use their own private resources and incomes to pay for needed services. Only 50 individuals per 1,000 age 40 or older in Washington have private long-term care insurance policies in effect.

Washington State is considered a national leader in the provision of home and community based services – in fact, 86 percent of individuals receiving Medicaid funded LTSS are served in their own home or community residential setting. According to the 2014 AARP Scorecard on Long-Term Services and Supports for older adults, people with physical disabilities and family caregivers, our LTSS system is ranked 2nd in the nation for its high performance at the same time as its ranking for cost is 34th.

Adults with dementia of every stage are served in programs and settings throughout the LTSS system. This has prompted, over time, the development of some dementia-specific services targeted to the particular needs of the population. Other services, while not dementia-specific, assist a substantial number of people living with memory loss or dementia.

Included below is an inventory of publicly-funded long-term services and supports available for people with Alzheimer’s or related dementias and/or their family caregivers.

SERVICES AVAILABLE THROUGH AGING & DISABILITY NETWORK

Area Agencies on Aging (AAAs) provide a network of community-based services funded by local, state and the federal Older Americans Act funding. The table below provides a summary of these services and programs. A number of programs offered through the Older Americans Act and State funds are required by all AAAs and others are discretionary and decisions about priorities and funding levels are made through the local Area Planning process.

Service/Program	Target Population	Description/Limitations
Memory Care & Wellness Services	Unpaid family caregivers who care for a person with a diagnosis of Alzheimer's disease or other dementia (care receiver).	Memory Care and Wellness Services is an evidence-informed, dementia-specific 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 <i>EnhanceMobility</i> .
	Funded through the Family Caregiver Support Program when the following criteria are met, including: The care receiver must live at home (not in a licensed care setting), and either live with the primary family caregiver or be receiving 40+ hours per week of care/supervision from the family caregiver. Caregiver eligibility is based on TCARE® assessed levels of burden, depression, etc. (See more on TCARE® in the Appendix, under the FCSP).	A University of Washington study of Memory Care and Wellness Services 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 and Wellness program.
		<u>Availability:</u> The Memory Care & Wellness Services program is available 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.

Service/Program	Target Population	Description/Limitations
Reducing Disability in Alzheimer's Disease	Individuals with Alzheimer's disease or other dementia with an available family caregiver to assist.	<p>Reducing Disability in Alzheimer's disease is an evidence-based, in-home exercise program that provides nine home visits by a trained, certified "coach" over a six-week period. The coach teaches caregivers how to encourage and safely supervise the care receiver while doing exercises, and how to address some problems that occur in older adults with memory problems or dementia.</p> <p>A University of Washington study of the Reducing Disability in Alzheimer's Disease program, showed significant short and long-term benefits for people in the treatment group. Physical functioning improved and fewer participants ended up in nursing homes due to behavioral disturbances.^{9,10}</p> <p><u>Availability:</u> The Reducing Disability in Alzheimer's Disease program is available in six Area Agencies on Aging. Funding is currently provided by a National Institute on Aging grant (2012-17). (See additional program descriptions in the appendix.)</p>
STAR-C Dementia Consultation (focus on Behavioral Problem-Solving)	<p>Unpaid family caregivers who care for a person with Alzheimer's disease or other dementia.</p> <p>Funded through the Family Caregiver Support Program (FCSP) when the following criteria are met, including: The care receiver must live at home (not in a licensed care setting), and must meet certain FCSP eligibility based on TCARE® assessed levels of burden,</p>	<p>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.</p> <p>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.^{11,12}</p> <p><u>Availability:</u> STAR-C Dementia Consultation is available through limited funding in five Area</p>

Service/Program	Target Population	Description/Limitations
	depression, etc. (See more on TCARE® in the Appendix under the FCSP).	Agencies on Aging. Further expansion would require additional infrastructure funding.
Community Living Connections (includes <i>Information and Assistance</i> ; known nationally as the <i>Aging and Disability Resource Center</i> <u>or</u> <i>No Wrong Door System</i>)	<p>Older adults (60+) or individuals with disabilities and/or their family/caregivers, regardless of economic circumstances.</p> <p>While not dementia-specific, Community Living Connections serves individuals and families living with memory loss/dementia.</p> <p>In order to offer care transitions coaching, different geographical areas have garnered different funding sources that target specific populations. No statistics specific to dementia/cognitive impairment are available. The evidence-based models are well suited to serve individuals with dementia or depression, provided they have willing and able informal caregivers.</p>	<p>The Community Living Connections (CLC) network provides individuals and families living with dementia a local access point to call for information, person-centered options counseling, care transition coaching, and assistance to access services. (See additional program descriptions in the Inventory Appendix.)</p> <p>Information-giving, options counseling, and access assistance are <u>available statewide</u> for older adults and individuals who are helping older adults. Also available is a statewide website and resource directory at www.waclc.org.</p> <p>Care Transitions coaching utilizes person-centered evidence-based models like <i>Care Transitions Intervention (CTI)</i> and <i>Bridges</i> to ensure the coordination and continuity of health care as patients transfer between different locations or different levels of care within the same location.</p> <p><u>Availability:</u> 11 of 13 AAAs have trained CTI coaches. (See Appendix for more information.)</p> <p>The CLC network is designed to serve persons of all ages and economic circumstances, with plans to expand service capacity and population expertise pending available funding and formalized statewide and local population-specific partnerships.</p>

Service/Program	Target Population	Description/Limitations
Aging & Disability Network Services (In-Home Services)	<p>Individuals age 60+, though delivery is targeted to the most vulnerable adults, including individuals with memory loss/dementia.</p> <p>National statistics indicate around 6% - 17% of clients served in these programs have a memory-related illness.</p> <p>Funded by Older Americans Act Title III.</p>	<p>The Aging & Disability Network consists of Area Agencies on Aging statewide that provide an array of home and community services including nutrition, transportation, adult day services, ombudsmen services, legal assistance, and support services and assistance.</p> <p>Services enhance the quality of life, social interaction, and reduce the effects of chronic illness or disability for homebound as well as more active seniors.</p> <p><u>Available statewide</u> through the 13 Area Agencies on Aging.</p>
Care Transitions	<p>Individuals of all economic backgrounds and ages however, different geographical areas have garnered different funding sources that target specific populations.</p> <p>No statistics specific to dementia/cognitive impairment are available. The model is well suited to serve individuals with dementia or depression, provided they have willing and able informal caregivers.</p>	<p>Care Transition services are a set of actions designed to ensure the coordination and continuity of health care as patients transfer between different locations or different levels of care within the same location.</p> <p>Washington State's <i>Aging & Disability Resource Center</i> project is concentrated on patient-centered hospital-to-home care transitions using an evidence-based coaching model, Care Transition Intervention®, developed by Eric Coleman and his team at the University of Colorado at Denver.</p> <p><u>Availability:</u> 11 of 13 AAAs have trained coaches. (See Appendix for more information.)</p>
Chronic Disease Self Management Program (CDSMP)	<p>Individuals who are age 18+ with one or more chronic conditions. Family, friends, and caregivers of people</p>	<p>The CSDMP is a collaboration between the ALTA, HCS, Washington State Department of Health (DOH), thirteen Area Agencies on Aging (AAA), and People First of Washington. This program was initiated through a federal</p>

Service/Program	Target Population	Description/Limitations
	<p>with chronic conditions are welcome to attend CDSME workshops.</p> <p>Workshops are appropriate for people living with early-stage memory loss and their caregivers.</p>	<p>grant ending February 29, 2016. By the end of the funding period, ALTSA will disseminate, design infrastructure, and plan sustainability for Stanford University's evidence-based Chronic Disease Self-Management Education (CDSME) programs.</p> <p>The specific types of CDSME program that Washington State is implementing are: 1) Chronic Disease Self-Management Program; 2) Tomando Control de su Salud; 3) Diabetes Self-Management Program; 4) Chronic Pain Self-Management; 5) Better Choices, Better Health (Online CDSMP).</p>
Family Caregiver Support Program (FCSP)	<p>Unpaid family caregivers of adults (18+) with functional disabilities.</p> <p>During an initial screening, callers are asked if the person they are caring for has problems with memory or cognition. Upon assessment, 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).</p>	<p>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); respite care; access to supplies/equipment; and support/practical information and caregiving suggestions.</p> <p>Several evidence-based services, mentioned above, are supported through Family Caregiver Support Program funding. (See Appendix for more information).</p> <p>Family Caregiver Support Program is <u>available statewide</u>.</p>
Legal Services	<p>Individuals 60 years of age or older with a focus is on socially and economically needy older individuals who</p>	<p>Legal Services Programs foster a cost-effective, high quality service that is integrated into the aging services network. The Legal Services Program provides access to the justice system by offering representation by a legal advocate (attorney,</p>

Service/Program	Target Population	Description/Limitations
	are experiencing legal problems.	<p>paralegal, or law student). Services provided include legal advice; brief legal services such as phone calls, letter writing, document review and drafting, or negotiation; representation at administrative hearings; representation in court; referral to other legal resources.</p> <p><u>Access Limitations:</u> Targeting of services to the most vulnerable adults is necessary due to funding limitations. This results in waiting times for services such as the CLEAR Senior legal hotline.</p>

MEDICAID STATE PLAN AND MEDICAID WAIVER SERVICES

The table below provides a summary of state plan and waiver services and programs that support individuals with care needs related to functional limitations. Programs provide services that meet the care needs of individuals with dementia, cognitive impairments, and physical limitations in community-based settings.

Service/Program	Target Population	Description/Limitations
Dementia Specialty Training	The Department of Social and Health Service's Dementia Specialty Training is required for administrators and long-term care workers in Adult Family Homes and Assisted Living Facilities, serving both Medicaid and non-Medicaid clients.	<p>Dementia Specialty Training is either an eight hour manager training or a six hour caregiver training. The instructors must complete the manager training and meet requirements to be approved by DSHS. Training provides instruction in caregiving skills that meets the special needs of people living with dementia. The course is instructor led and is accompanied by a DVD and a student workbook.</p> <p>Upon completion, students gain a basic understanding of dementia and demonstrate awareness of the unique needs of residents with dementia. They also learn best practices for providing dementia care, including communication strategies, dealing with challenges of behavior and enhancing daily living.</p>
Specialized Dementia Care Program in Assisted Living Facilities (SDCP)	<p>Individuals who are both COPES and Specialized Dementia Care Program-eligible with Alzheimer's disease or other dementia and receiving care in a facility contracted to provide Specialized Dementia Care Program services.</p> <p>Specialized Dementia Care Program eligibility</p>	<p>Specialized Dementia Care Program (SDCP) services are provided within SDCP-contracted Assisted Living Facilities, which must be either dedicated solely to the care of persons with dementia, or providing such care to persons with dementia in a separate unit dedicated solely to the care of persons with dementia within larger facilities.</p> <p>The Assisted Living Facility must be contracted with DSHS to provide Specialized Dementia Care Services, which include: care, supervision, and activities tailored to the specific needs, interests, abilities, and preferences of the person; coordination with the person's family to ensure the person's routines and preferences</p>

Service/Program	Target Population	Description/Limitations
	<p>is defined in WAC 388-106-0033.</p> <p>In 2014, the Specialized Dementia Care Program served 932 clients. (See Appendix for more information.)</p>	<p>are honored; dementia specific training for staff; awake staff twenty-four hours a day; a safe outdoor environment with walking paths and access to a secure outdoor area; and intermittent nursing services, help with medications, personal care, and other support services.</p> <p>The Specialized Dementia Care Program is <u>available statewide</u>, based upon availability of qualified providers. Currently, there are 61 contractors.</p>
Community Options Program Entry Services (COPES)	<p>To be eligible for Community Options Program Entry Services (COPES), individuals must be age 18 or older and blind, aged, or disabled per Social Security criteria; meet Nursing Facility Level of Care (NFLOC) criteria and income requirements, and live in their own home, Assisted Living Facility, or Adult Family Home. See Appendix for more on NFLOC.</p> <p>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.</p>	<p>COPES provides client training, skilled nursing, home delivered meals, home modifications, specialized medical equipment and supplies, transportation, adult day care, adult day health, and home health aides.</p>
Community First Choice (CFC)	<p>To be eligible for Community First Choice, individuals may</p>	<p>CFC will provides personal care assistance, skills acquisition training, Personal Emergency Response Systems (PERS), training on how to</p>

Service/Program	Target Population	Description/Limitations
	<p>be of any age, and have functional limitations due to age, physical, cognitive, intellectual, or mental health conditions and unmet needs for personal care; meet institutional level of care and income requirements; and live in their own home, Assisted Living Facility, or Adult Family Home. See Appendix for more on NFLOC.</p>	<p>manage a paid care provider, community transition services, nurse delegation, and assistive technology that substitutes for human assistance.</p>
<p>Enhanced Service Facility (ESF)</p>	<p>ESFs 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.</p> <p>To be eligible, clients must meet Nursing Facility Level of Care (NFLOC) and Enhanced Service Facility criteria. This new Medicaid program will be funded</p>	<p>Enhanced Service Facilities offer behavioral supports, personal care assistance, medical or habilitative treatment, dietary services, security, chemical dependency treatment, and supervision in a specialized residential facility.</p> <p>The first ESF bed will open in the fall of 2015.</p>

Service/Program	Target Population	Description/Limitations
	through a 1915(c) waiver.	
Expanded Community Services (ECS)	<p>Expanded Community Services are designed for clients with exceptional care needs due to behavioral or mental health issues when current services are not adequate for successful placement due to significant behavioral challenges.</p> <p>To be eligible, clients must meet COPES and Expanded Community Services program criteria.</p> <p>Approximately one-quarter of individuals served in Expanded Community Services (3013) had behaviors related to dementia.</p>	<p>Expanded Community Services offers an enhanced rate to specifically-contracted COPES residential providers or Expanded Community Services-contracted skilled nursing facility providers; and behavioral support services that are provided through contracts with COPES Expanded Community Services Behavior Support providers or through the Skilled Nursing Facility enhanced rate.</p>
Health Home Services	<p>Individuals with chronic illnesses who are eligible for Medicaid or both Medicare and Medicaid.</p> <p>Individuals must also be at significant risk for health problems that can lead to unnecessary use of hospitals, emergency rooms, and other expensive institutional</p>	<p>Health Home Services provide integration and coordination of primary, long-term services and supports, and behavioral health/substance use services. They are most commonly focused on individuals with one or more chronic health conditions.</p> <p>A Health Home provides six specific services beyond the clinical services offered by a typical primary care provider: comprehensive care management, care coordination and health promotion, comprehensive transitional care and follow-up, patient and family support, referral to community and social support</p>

Service/Program	Target Population	Description/Limitations
	settings. (See Appendix for more information.)	services, and use of information technology to link services, if applicable.
Medicaid Personal Care (MPC)	Individuals who meet the functional criteria based on the social service assessment and financial eligibility based on eligibility for a <u>non-institutional</u> categorically needy or Alternative Benefit Plan Medicaid Program. Functional eligibility for this program is based on Chapter 388-106 WAC .	<p>Medicaid Personal Care is a program allowed under Washington State's Medicaid State Plan that provides assistance with activities of daily living to eligible individuals.</p> <p>Activities of daily living include tasks such as bathing, dressing, eating, toileting, transferring, ambulating, etc.</p> <p>Medicaid Personal Care services are available in the client's own home, an Adult Family Home, or an Adult Residential Center.</p>
New Freedom Consumer Directed Services Program	<p>Individuals who are 18+ and blind, aged, or disabled per Social Security criteria; have functional disabilities based on medical issues or chronic illness; live in their own homes; and meet Nursing Facility Level of Care and income requirements (see Appendix for more information).</p> <p>Funded through 1915(c) Medicaid waiver.</p>	<p>New Freedom is a voluntary budget-based program that provides participants, who are eligible for home and community-based services through the Medicaid waiver, the opportunity for increased choice and control over their services and supports.</p> <p><u>Availability:</u> New Freedom is currently operating in King and Pierce Counties.</p>
Program of All-Inclusive Care for the Elderly (PACE)	Individuals must be age 55 or older, meet Nursing Facility Level of Care (NFLOC), and live in the PACE service	The PACE program is a fully integrated managed care program that includes an Adult Day Health center component. PACE clients receive transportation to and from the PACE center to receive physical, occupational, speech therapy;

Service/Program	Target Population	Description/Limitations
	area. PACE is currently offered only in King County.	medications; nursing services; clinic visits; meals and activities. The center includes quiet space, activities, and a “wandering walk” tailored specifically to clients with dementia.

LONG-TERM SERVICES, SUPPORTS SETTINGS, AND PROVIDER TYPES

Long-Term Services and Supports are provided in a number of settings and by many different types of providers. The table below provides a summary of the types of long-term care settings, providers, and non-Medicaid services.

Service/Program	Target population	Description/Limitations
Assisted Living Facilities (ALF) 541 in WA as of August 2015	ALFs are available to individuals who are age 18 and older requiring support and supervision. Services vary depending on the type of contract the ALF obtains from the Aging and Long-Term Support Administration (AL TSA).	<p>An assisted living facility (ALF), formerly called a boarding home, is a community setting licensed to care for seven or more residents. The majority are privately owned businesses. The facility provides housing, basic services and assumes general responsibility for the safety and well-being of the resident. The majority of residents pay for their care privately. ALFs allow residents to live an independent lifestyle in a community setting while receiving necessary services from staff. ALFs can vary in size and ownership from a family operated 7-bed facility to a 150-bed facility operated by a large national corporation. Some ALFs provide intermittent nursing services or may serve residents with mental health problems, developmental disabilities, or dementia.</p> <p>ALFs that contract with AL TSA provide one or more of the following service packages:</p> <p>Assisted Living</p> <p>Private apartments, with an emphasis on privacy, independence, and personal choice</p> <p>Intermittent nursing services</p> <p>Medication administration and personal care services</p> <p>Adult Residential Care (ARC)</p> <p>Medication assistance and personal care services</p> <p>Residents may need/receive limited supervision</p>

Service/Program	Target population	Description/Limitations
		<p>Enhanced Adult Residential Care (EARC)</p> <p>Medication administration and personal care services</p> <p>No more than two people will share a room</p> <p>Intermittent nursing services</p> <p>Specialized Dementia Care Program (EARC-SDC)</p> <p>In a SDCP-contracted ALF which is dedicated solely to the care of persons with dementia, or providing such care within a unit dedicated solely to the care of person with dementia.</p> <p>Includes service package of EARC plus services outlined SDCP paragraph above.</p>
<p>Adult Family Homes (AFH)</p> <p>2,767 in WA as of August 2015</p>	<p>AFHs are available to anyone over age 18 requiring support and supervision.</p>	<p>Adult Family Homes (AFHs) are regular residential homes licensed to care for two to six residents. 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 or other special care and services. Primary authority for adult family homes can be found in Chapter 388-76 WAC and Chapter 70.128 RCW.</p> <p>Residents can pay privately or be funded through DSHS. AFH residents have the right to exercise reasonable control over life decisions. See www.aasa.dshs.wa.gov/Professional/afh/AFHinfo.htm for additional information on Resident Rights and more.</p>
<p>In-Home Care Service Agencies</p> <p>438 in WA as of August 2015</p>	<p>Individuals who may be ill, disabled, or vulnerable, and wish to remain in a community-based setting.</p>	<p>In-home care service agencies are licensed to administer or provide home health, home care, hospice or hospice care center services directly or through a contract arrangement to patients or clients in a place of temporary or permanent residence.</p>

Service/Program	Target population	Description/Limitations
		<p>Home health services: This may include nursing services, home health aide services, physical therapy services, occupational therapy services, speech therapy services, respiratory therapy services, nutritional services, medical social services, home medical supplies or equipment services, and professional medical equipment assessment services.</p> <p>Home care or non-medical services: This 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 delegated tasks of nursing.</p> <p>In-home care hospice services: This may include symptom and pain management provided to a terminally ill patient, and emotional, spiritual and bereavement support for the patient and family in a place of temporary or permanent residence, including hospice care centers, and may include the provision of home health and home care services for the terminally ill patient through an in-home services agency licensed to provide hospice or hospice care center services.</p> <p>Hospice care center: Provided in a homelike non-institutional facility, services may include continuous care, general inpatient care, inpatient respite care, and routine home care.</p>
Skilled Nursing Facility Care (SNF) 229 in WA as of August 2015	Individuals whose conditions are complex and/or medically unstable and who require frequent medical or nursing intervention.	Skilled nursing facilities have nursing services available 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.

Service/Program	Target population	Description/Limitations
Independent or Individual Provider	Individuals who need assistance with personal care or respite services.	Independent or Individuals Living Providers provide personal care or respite services in the home. The individual who requires care hires the Independent or Individuals Living Provider; providers are paid privately or through DSHS.
Adult Day Centers 40 in WA as of August 2015	Individuals who have an unmet need for personal care services, routine health monitoring with consultation from a registered nurse, general therapeutic activities, or supervision and/or protection.	<p>Adult Day Care (ADC) is a supervised daytime program providing core services for adults with medical or disabling conditions that do not require the intervention or services of a registered nurse or licensed rehabilitative therapist acting under the supervision of the client's authorizing practitioner. Services may include personal care, routine health monitoring, health education, nutritious meals or supervision/protection.</p> <p>Adult Day Health (ADH) is a supervised daytime program providing skilled nursing and/or rehabilitative therapy services in addition to the core services of adult day care. Adult day health services may also include physical therapy, Speech-language pathology, audiology, or counseling services.</p> <p>Memory Care & Wellness Services (MCWS) is an evidence-informed, dementia-specific 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 <i>EnhanceMobility</i>.</p>
Continuing Care Retirement Communities (CCRCs)	Individuals who wish to live in an independent living setting but expect to need personal care or skilled nursing assistance at some point in the future.	<p>CCRCs give older adults the option of living in one location for the duration of their life while guaranteeing that additional care will be provided when needed. Individuals can move into a CCRC when they are fully independent and access assisted living, personal care, and skilled nursing as their needs change.</p> <p>CCRCs have various levels of contract types. Individuals may enter into CCRCs with different levels of financial commitment and service level</p>

Service/Program	Target population	Description/Limitations
		agreements. Entry fees and monthly fees are typically included in the service agreement.
State-Funded Volunteer Services	Adults age 18+ living at home and unable to perform certain personal care tasks due to a functional or cognitive impairment and not receiving services under Medicaid long-term services and supports.	Volunteer services provide assist with general household tasks. Tasks may include housekeeping, laundry, shopping, cooking, moving, minor home repair, yard care, and transportation.
Transportation <i>Public Transportation</i> <i>Dial-a-Ride</i> <i>Paratransit</i>	Individuals who need transportation to medical and health services, social services, meal programs or for shopping assistance and cannot provide or arrange their own transport because they do not have a car, are unable to drive, cannot afford to drive, or require assistance to access public transportation.	Transportation services assist eligible clients with getting to and from social services, medical and health care services, meal programs, senior centers, essential shopping, and some recreational activities. Transportation services may include personal assistance for those with limited physical mobility, door-to-door service, individually scheduled rides to appointments, and reduced fares.
Homecare Referral Registry (HCRR)	Medicaid eligible clients and families receiving Long-Term Supports and Services through HCS/AAA or DDA who choose to hire and supervise their own in-home individual providers of respite or personal care.	The Home Care Referral Registry supports consumers and families by providing a list of pre-screened, work-ready providers using web-based matching-logic programing. Local support and educational materials are available from Registry Coordinators positioned across the State. Pre-screened providers are assisted by Registry Coordinators to initiate an Individual Provider contract with the department, meet and maintain training and certification

Service/Program	Target population	Description/Limitations
		<p>requirements, and get matched with interested consumers.</p> <p><u>Limitations:</u> Personal assistance matching services offered are not available in Chelan, Douglas and Okanogan counties.</p>
Personal Emergency Response Systems (PERS)	Individuals living independently who are at risk of falling or having a medical emergency that would make it difficult to call for help.	<p>Although there are a wide variety of products PERS (also called Medical Alert Systems) typically consist of a small button-sized transmitter that may be carried or worn, a receiving console that is connected to a telephone, and a monitoring center which may be nationally or locally based.</p> <p>A number of companies offer this service with differences in contract terms, technology, level of service, and cost that the user should be aware of. Companies provide this service by selling devices, renting devices, or providing paid monthly services. In some cases the cost of the device may be subsidized by another program.</p> <p>Depending on the type of system used, service provided may include storing relevant medical information with a monitoring center, GPS location, 24/7 monitoring, direct communication with an monitoring center dispatcher, fall detection, an auto call to the identified the emergency contact, or an auto call to 911.</p>
Senior Centers	Individuals who would benefit from supplemental meals, a service point connection, or the social support of a communal setting.	Senior centers are facilities in a community where older people can meet, share a meal, get services, and take part in health, wellness, and recreational activities. Senior centers also serve as a referral hub, providing information about and referrals to services that may benefit older individuals.
Senior Nutrition	Individuals not able to prepare nutritious meals due to limited	Nutritious meals are provided in community (congregate) settings or through home-delivery

Service/Program	Target population	Description/Limitations
	mobility, cognitive impairment, lack of knowledge or skills, or lack of incentive to prepare and eat meals alone.	<p>for individuals who have difficulty leaving their homes.</p> <p>Meals provided in a congregate setting meet at least one-third of the current Recommended Dietary Allowance and allow for special dietary needs. Home-delivered meals are provided at least once a day, five or more days a week. Meals may be hot, cold, frozen, dried, canned or supplemental foods with a satisfactory storage life.</p> <p>Additional senior nutrition services include outreach, case management, and referral to other types of services individuals may benefit from.</p> <p><u>Limitations:</u> Due to federal sequestration for Older American's Act funds, services have been reduced in many regions as the cost to provide a meal rises.</p>
Office of Deaf and Hard of Hearing (ODHH)	Individuals who are deaf, hard of hearing, deaf-blind, or speech disabled.	<p>ODHH provides services to facilitate equal access to effective communication. Services are designed to be person-centered and recognize the wide range of communication preferences among various individuals.</p> <p>Telecommunications services provided by ODHH may include relay services, distribution of specialized equipment, videophone services, sign language interpreter services, assisted listening devices, and communication access real-time translation (CART) services. Other services provided may include case management, education and training, information and referral, outreach, and independent living assistance.</p>
Department of Social and Health Services (DSHS)	Individuals in need of multiple types of social services in order to meet their basic needs and attain life stability.	DSHS act as a resource network with individuals frequently accessing services and supports across administrations and divisions.

Service/Program	Target population	Description/Limitations
		<p>Economic Services Administration Service areas include food assistance (food stamps) and financial assistance.</p> <p>Division of Behavioral Health and Recovery Service areas include mental health, substance abuse and problem gambling prevention and treatment.</p> <p>Developmental Disabilities Administration Service areas include residential supports, personal care, employment supports, respite care, and case management.</p> <p>Aging and Long-Term Support Administration Service areas include community living and residential care supports, personal care supports, dementia care, family caregiver support, and case management.</p>

PROTECTIVE SERVICES

Protective services safeguard the right of vulnerable adults to live a life free from mistreatment and abuse, financial exploitation, self-neglect, neglect by others, and abandonment. The table below provides a summary of these services and programs.

Service/Program	Target population	Description/Limitations
Adult Protective Services (APS)	Any adult 60+ who cannot care for him or herself; or adults 18+ that have a legal guardian; have a developmental disability, etc. (see full definition of target population/eligibility in Appendix).	<p>APS receives and investigates allegations of abuse (physical, mental, sexual, and exploitation of person), 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.</p> <p>APS is <u>available statewide</u> to individuals of all income levels.</p> <p>To make a report: Call 1-866-ENDHARM (1-866-363-4276) to report suspected abuse or neglect of a child or a vulnerable adult.</p>
Long-Term Care Ombudsman	Residents living in a care facility and his/her relatives or friends.	The Long-Term Care Ombudsman Program is a federally mandated program which works to protect and promote rights of individuals living in licensed, long-term adult care facilities (e.g. adult family home, assisted living facility, nursing home). This is accomplished by providing information to consumers about their long-term care options, working to resolve problems on behalf of residents, and advocating for improvement in the long-term care system.
Office of Public Guardianship	Low-income individuals age 18+ that are receiving long-term care services; have been determined to the superior court to be incapacitated to make personal, medical, or financial decisions; and do not have a	<p>A guardian is a surrogate decision-maker, appointed by the court to make either personal and/or financial decisions for a minor or adult, who the court has determined has a significant risk of personal and/or financial harm based on a demonstrated inability to adequately provide for his/her nutrition, health, and physical safety or to manage their financial affairs and/or personal property.</p> <p>The Office of Public Guardianship provides public guardianship services to incapacitated</p>

Service/Program	Target population	Description/Limitations
	qualified or willing guardian.	<p>individuals who do not have family a member to serve as a guardian or the have financial resources to pay for a guardian.</p> <p><u>Limitations:</u> Currently the program is only available in Clallam, Grays Harbor, King, Okanogan, Pierce, Snohomish, Spokane, Clark, Kitsap and Thurston Counties. In recent years, funding has been severely cut, and no new cases are being accepted absent additional funding. Also, Office of Public Guardianship can assist only with the provision of guardianship services, and cannot serve as agent with a power of attorney, payee, trustee, or provide counseling or other assistance with end-of-life decision-making.</p>

INVENTORY APPENDIX: ADDITIONAL INFORMATION

Adult Family Home – A residential home in which a person or persons provide personal care, special care and room and board to more than one but not more than six adults who are not related by blood or marriage to the person or persons providing the services. Adult family homes may also be designated as a specialty home (on their license) in one or more of the following three categories: Developmental Disability, Mental Illness, and Dementia if they meet all certification and training requirements. See **Chapter 388-76 WAC** for more on adult family home licensing requirements.

Adult Protective Services target population - A Vulnerable Adult is: any adult 60+ who cannot care for him or herself; or adults 18+ that have a legal guardian; have a developmental disability; live in a facility licensed by DSHS; 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. More on Adult Protect Services can be found at: www.adsa.dshs.wa.gov/APS/

Aging and Disability Network Services - The National Aging Network (the Aging Network) was established in 1965 with the passage of the Older Americans Act and is one of the Nation's largest provider networks of home and community-based care for older persons, adults with disabilities and their caregivers. The Administration on Aging, an agency in the U.S. Department of Health and Human Services, is a lead partner of the Aging Network which consists of 56 State Units on Aging, 629 Area Agencies on Aging, 246 Tribal organizations, 20,000 service providers, and thousands of volunteers.

Area Agencies on Aging (AAAs) – local organizations that develop and promote services and options to maximize independence for elders, adults with disabilities, and family caregivers. Washington has thirteen Area Agencies on Aging that are comprised of county governments, regional councils, and tribes. A citizen advisory council guides the work. The Washington Association of Area Agencies on Aging is a membership organization made up of the 13 Area Agencies on Aging in Washington State that seeks to enhance the effectiveness of each AAA through a strong agenda of information, debate, advocacy and education.

Assisted Living Facility – a facility, 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** for more on assisted living licensing requirements.

Community Living Connections (CLC) – known nationally as *Aging and Disability Resource Centers* or *No-Wrong-Door*, serve as integrated and unbiased focal points to make it easier for consumers to learn about and access long-term services and supports (LTSS). Serving persons of all ages and economic circumstances, CLCs provide: objective information about the full range of available public and private LTSS options; person-centered options and benefits counseling, person-centered plan development support; and help as needed and desired for plan implementation, including accessing services.

As part of their role, CLCs also provide evidence-based **care transition coaching**; where patients (or their caregivers) learn self-management skills to ensure their needs are met during the transition from one setting or care-level to another. Patients who participate in care transition coaching are significantly less likely to be readmitted and more likely to achieve self-identified personal goals around symptom management and functional recovery, for as long as six to nine months. Community Living Connections relies on strong partnerships with other social services organizations; health care providers; and aging and disability advocates to create integrated cross-referring networks. A statewide website with resource directory and a toll-free number are available to further support consumers in learning about their options and how to access services.

Community Options Program Entry System (COPES) Waiver – The COPES waiver was implemented in 1982 and is one of the oldest waivers in the nation. COPES services are funded with a combination of state dollars and with Title XIX (Medicaid) federal dollars. The Aging and Long-Term Support Administration partners with the Centers for Medicare and Medicaid Services and the Area Agencies on Aging to implement the COPES waiver.

COPES services are an effective alternative to nursing home placement and are an integral component of Washington State’s successful rebalancing of services from institutional to community-based settings.

Family Caregiver Support Program – The Family Caregiver Support Program (FCSP) services unpaid family caregivers. It integrates an evidence-based caregiver assessment/ consultation and care planning process known as TCARE® - Tailored Caregiver Assessment & Referral®.

The *Tailored Caregiver Assessment and Referral (TCARE®)* system was created by Rhonda Montgomery, PhD and colleagues at the University of Wisconsin-Milwaukee. The TCARE® protocol is designed to tailor services to the unique needs of each caregiver thereby reducing stress, depression and burdens associated with caregiving. TCARE® provides a consistent, objective and reliable screening and assessment process that identifies at-risk caregivers, targets resources to those most in need and determines whether support and services make a measurable difference to caregivers. TCARE® also helps inform policy through the collection of statewide data. The effectiveness of TCARE® is documented in published research articles based upon a national randomized control study, in which Washington State participated. For more information, visit the national TCARE® website at www.TCARE.uwm.edu.

Health Home Services – Health Home services are available to individuals with chronic illnesses and who are eligible for Medicaid or both Medicare and Medicaid. Individuals must also be at significant risk for health problems that can lead to unnecessary use of hospitals, emergency rooms, and other expensive institutional settings such as psychiatric hospitals and nursing homes. Washington uses a predictive risk modeling system called PRISM to identify individuals who are at significant risk.

Individuals receiving Health Home services are assigned a Health Home coordinator who partners with beneficiaries, their families, doctors, and other agencies providing services to ensure coordination across these systems of care. The health home coordinator visits in-person

and is also available by telephone to help the individual, their families, and service providers. For more information, go to: www.hca.wa.gov/Pages/health_homes.aspx

Memory Care & Wellness Services – A supervised daytime program for individuals with dementia and their family caregivers. Memory Care & Wellness Services (MCWS) offers a program that is a blend of health, social and family caregiver supports – it is defined and requirements are specified in the “Memory Care & Wellness Services Standards of Care, December 2010” (currently under refinement).

Memory Care & Wellness Services build upon the core services listed under Adult Day Care and add the following: A program day of five hours, offered two days per week; staffing that accommodates increasing functional and behavioral support needs of participants as they progress in their dementia, including: 1:4 (vs.1:6) staff to client ratio; and skilled nursing and/or therapy and social services available during program hours for the participant with targeted education and support of the family caregiver, as needed. A structured, specialized exercise program, *EnhanceMobility* is integrated into the program.

Started through federal Alzheimer’s demonstration grants, this program has demonstrated that for individuals with dementia, quality of life improved and the frequency of behavior problems decreased. For family caregivers, distress over behavior problems decreased in participating caregivers while increasing in comparison group caregivers. Depressive symptoms, stress and burden also decreased. (Logsdon et al, 2014)

Memory Care and Wellness Services are currently available in 3 of 13 Area Agency on Aging (AAA) service areas. Original service areas (King County and Northwest WA AAAs) are now supporting MCWS through limited MCWS-funding within the Family Caregiver Support Program budget; a federal Pierce County demonstration grant will end Aug. 31, 2014 and may need additional funding to be sustained.

Nursing Facility Level of Care (NFLOC) criteria – The individual must: require care provided by or under the supervision of a registered nurse or a licensed practical nurse on a daily basis; have an unmet or partially met need with at least three ADLs as defined in WAC 388-106-0355; or have cognitive impairment and require supervision due to one or more of the following: disorientation, memory impairment, impaired decision-making, or wandering and have an unmet or partially met need with an ADL as defined in WAC 388-106-0355.

Reducing Disability in Alzheimer’s disease (RDAD) – RDAD is an evidence-based, in-home exercise program consisting of nine home visits by a specially-trained/certified RDAD "coach" over a six-week period.

RDAD research at the University of Washington demonstrated significant short and long-term benefits for people in the treatment group. Physical functioning improved and fewer participants ended up in nursing homes due to behavioral disturbances. (Teri et al, 2003; Logsdon et al, 2005)

During the one-hour in-home sessions, the coach teaches easy-to-follow exercises to both the caregiver and care receiver (i.e. the person with dementia). The coach teaches the caregiver how to encourage and safely supervise the care receiver while doing the exercises. The coach also teaches caregivers how to handle some of the problems that occur with older adults who have memory problems or dementia.

RDAD is currently being translated through a National Institute on Aging grant (2012-17), with Washington (and Oregon) AAAs in the following Washington areas: Olympic, King County, Pierce, Snohomish, Southwest WA and Southeast WA. The federal grant is in operation from 2012-2017.

Specialized Dementia Care Program (SDCP) – Initiated as a partnership with providers, stakeholders and the University of Washington (1999), the SDCP demonstrated the ability to accept and retain individuals with greater cognitive impairment and behavioral disturbances than traditional assisted living programs. For more information, see the University of Washington’s final outcome report on the [Dementia Care Pilot Project](#), 2003.

Participation in SDCP has shown to significantly delay nursing home placement. Based on the positive pilot project findings, 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](#).

STAR-C – STAR-C is an evidence-based dementia consultation program designed to help caregivers reduce or eliminate behaviors that are difficult to manage, such as anxiousness, resistance to care, wandering, or verbal or physical aggression.

This in-home education/consultation program, developed at the University of Washington, has shown to improve care receiver quality life, reduce the frequency of problem behaviors, and lower caregiving depression, burden, and distress over care receiver behavior changes. (Teri et al, 2005; Logsdon et al, 2005) STAR-C is implemented in the caregivers’ homes by skilled consultants who are certified by the University of Washington to deliver STAR-C. It is now delivered over a six-week period, with 4 home visits and additional phone support.

STAR-C was first translated in Oregon through a federal demonstration grant and then modified into a condensed version in Oregon and Washington (2012-2014). It is now being continued in two service areas in Oregon and implemented in the following Washington areas: Central WA, King County, Lewis/Mason/Thurston AAA, Northwest WA, Southwest WA and Southeast WA.

Funding to pilot a translation of STAR-C into Washington’s Family Caregiver Support Program occurred through Older Americans Act (OAA) Title III administrative funding in partnership with the University of Washington, ALTSA and participating AAAs (using local FCSP funds to support service delivery). While the pilot has resulted in positive feedback from participating caregivers and AAAs along with the development of basic processes for certification of community consultants and integration into the FCSP, further expansion would require additional infrastructure for ongoing sustainability and fidelity to this evidence-based practice.

REFERENCES

- Logsdon RG, Pike KC, Korte L, & Goehring C. Memory Care and Wellness Services: Efficacy of specialized dementia care in adult day services. The Gerontologist. doi:10.1093/geront/gnu012. (2014, in press).
- Logsdon RG, McCurry SM, & Teri L. A home health care approach to exercise for persons with Alzheimer's disease. Care Management Journals: Journal of Long-Term Home Health Care 2005 6(2), 90-97
- Logsdon RG, McCurry SM, & Teri L. STAR-Caregivers: A community-based approach for teaching family caregivers to use behavioral strategies to reduce affective disturbances in persons with dementia. Alzheimer's Care Quarterly 2005; 6 (5), 146-153
- Teri L, Gibbons LE, McCurry SM, Logsdon RG, Buchner DM, Barlow WE, Kukull WA, LaCroix AZ, McCormick WC, Larson EB. Exercise Plus Behavioral Management in Patients with Alzheimer Disease: A Randomized Controlled Trial. JAMA 2003; 290(15)
- Teri L, McCurry SM, Logsdon RG, & Gibbons LE. Training community consultants to help family members improve dementia care: A randomized controlled trial. The Gerontologist 2005; 45(6), 802-811

APPENDIX F: PREVALENCE AND FORECASTS OF THE DEMENTIA POPULATION

POPULATION ESTIMATES

The baby boom generation, people born between 1946 and 1964, are stepping in to retirement. Those born in 1964 will be 51 this year, and those born in 1946 are now 69. Age is the best known risk factor for developing Alzheimer's and other dementias.¹ Additional factors compound the issues of increasing numbers of people with dementia and providing care, including the growth of the "oldest-old" population, and the steady increase in the number of people living alone.

GROWTH OF DEMENTIA

David Mancuso, PhD, Director of the Department of Social and Health Services Research and Data Analysis Division estimates that between 77,000 and 96,000 Washington residents age 65+ had Alzheimer's disease, dementia or serious cognitive difficulty in 2010. Using prevalence projections and population estimates, we expect between 215,000 and 270,000 people age 65 or older will have a form of dementia in 2040.^{2,3,4} This represents an increase of 152% to 181%, depending upon the prevalence estimates used.

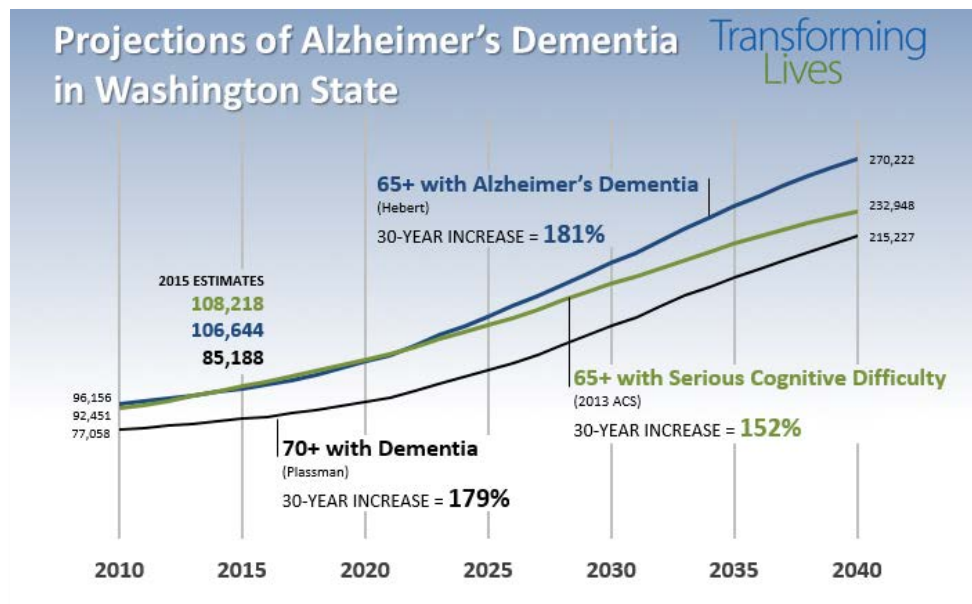


Figure 1. Projection of Alzheimer's disease in Washington State from three separate studies.

Our aging population compounds service and access issues for long-term supports and services, not just for people with dementia, but others who need support with activities of daily living. In the maps below, one can see the growth of the state's population age 65+. In 2030,

about 19 counties, mostly in rural areas, will have about a third of their population age 65 or older. In Wahkiakum County in 2030, over 4 in 10 residents will be age 65 or older.

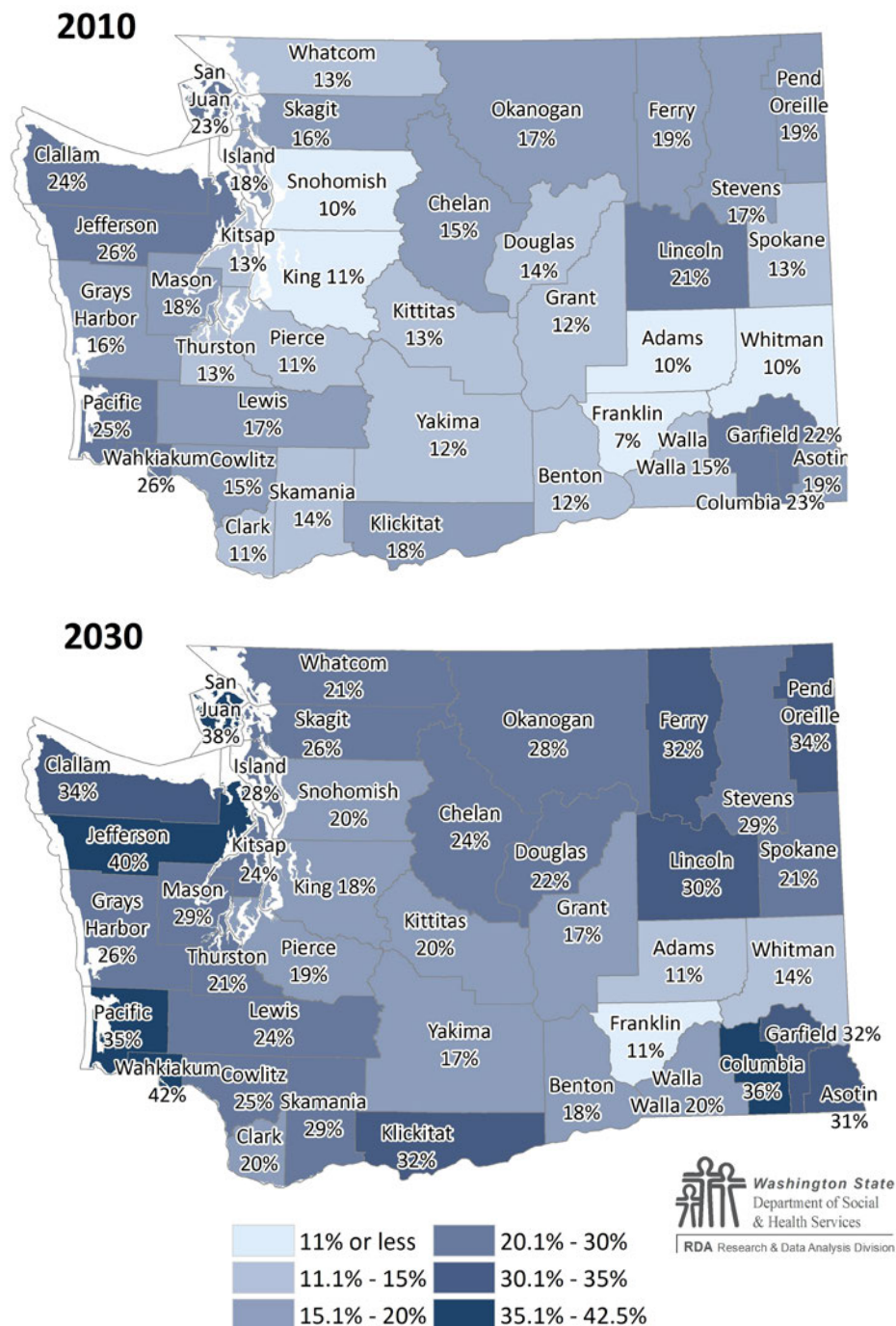


Figure 2. Washington State 65+ Population by County, 2010 - 2030. Source: Department of Social and Health Services Research and Data Analysis, Office of Financial Management, Forecasting and Research Division.

Table 1. Projected persons 65+ with Alzheimer's disease in Washington counties: 2015-2040, based on national prevalence rates (Hebert, 2013). Source: Washington State Department of Social and Health Services, Research and Data Analysis Division, Olympia, WA, April 22, 2015.

County	Projected Persons 65+ with Alzheimer's Disease				Prevalence Rate				Average Annual Growth Rate			
	2015	2020	2030	2040	2015	2020	2030	2040	2015-2020	2020-2030	2030-2040	2015-2040
Adams	237	255	331	406	11.2%	10.8%	12.0%	13.3%	1.5%	2.6%	2.1%	2.2%
Asotin	566	680	958	1,175	11.3%	11.5%	13.5%	17.1%	3.7%	3.5%	2.1%	3.0%
Benton	2,672	3,229	4,973	6,764	10.4%	10.2%	11.8%	14.7%	3.9%	4.4%	3.1%	3.8%
Chelan	1,479	1,681	2,520	3,424	11.2%	10.4%	11.9%	15.4%	2.6%	4.1%	3.1%	3.4%
Clallam	2,182	2,468	3,269	3,958	11.4%	11.2%	12.5%	16.0%	2.5%	2.9%	1.9%	2.4%
Clark	6,346	7,944	13,052	18,530	10.1%	10.1%	12.1%	14.6%	4.6%	5.1%	3.6%	4.4%
Columbia	121	145	200	222	10.7%	11.4%	14.0%	18.1%	3.7%	3.3%	1.1%	2.5%
Cowlitz	1,995	2,359	3,493	4,509	10.4%	10.3%	12.1%	15.0%	3.4%	4.0%	2.6%	3.3%
Douglas	718	888	1,372	1,881	10.7%	10.8%	12.5%	15.4%	4.4%	4.4%	3.2%	3.9%
Ferry	171	225	330	380	9.5%	9.9%	12.9%	16.9%	5.6%	3.9%	1.4%	3.2%
Franklin	739	934	1,582	2,454	10.1%	9.7%	11.3%	12.7%	4.8%	5.4%	4.5%	4.9%
Garfield	68	70	93	104	12.5%	10.9%	13.0%	16.7%	0.3%	2.9%	1.2%	1.7%
Grant	1,338	1,626	2,441	3,424	10.4%	10.5%	11.7%	13.8%	4.0%	4.1%	3.4%	3.8%
Grays Harbor	1,447	1,670	2,416	2,995	10.2%	10.1%	11.9%	15.0%	2.9%	3.8%	2.2%	3.0%
Island	1,810	2,169	3,071	3,830	10.3%	10.5%	12.3%	15.6%	3.7%	3.5%	2.2%	3.0%
Jefferson	949	1,183	1,807	2,293	9.7%	10.1%	12.5%	16.5%	4.5%	4.3%	2.4%	3.6%
King	27,887	32,382	48,984	67,797	10.7%	10.2%	11.6%	14.1%	3.0%	4.2%	3.3%	3.6%
Kitsap	4,316	5,463	9,029	12,124	9.8%	9.8%	12.1%	15.5%	4.8%	5.2%	3.0%	4.2%
Kittitas	633	781	1,193	1,575	10.1%	10.2%	11.9%	14.7%	4.3%	4.3%	2.8%	3.7%
Klickitat	450	590	910	1,101	9.5%	9.9%	12.9%	16.2%	5.6%	4.4%	1.9%	3.6%
Lewis	1,631	1,845	2,496	3,080	10.9%	10.8%	12.0%	15.0%	2.5%	3.1%	2.1%	2.6%
Lincoln	280	322	424	482	10.9%	11.0%	12.7%	16.5%	2.8%	2.8%	1.3%	2.2%
Mason	1,391	1,702	2,575	3,486	10.4%	10.3%	11.6%	15.0%	4.1%	4.2%	3.1%	3.7%
Okanogan	902	1,113	1,638	1,968	10.0%	10.2%	12.7%	16.1%	4.3%	3.9%	1.9%	3.2%
Pacific	644	758	1,010	1,160	10.7%	10.9%	13.1%	16.6%	3.3%	2.9%	1.4%	2.4%
Pend Oreille	307	406	629	761	9.4%	9.9%	12.7%	16.9%	5.7%	4.5%	1.9%	3.7%
Pierce	10,903	12,972	20,904	30,195	10.2%	9.8%	11.1%	13.9%	3.5%	4.9%	3.7%	4.2%
San Juan	457	586	879	1,029	9.4%	9.9%	13.2%	17.0%	5.1%	4.1%	1.6%	3.3%
Skagit	2,472	2,955	4,593	6,267	10.6%	10.3%	12.0%	15.0%	3.6%	4.5%	3.2%	3.8%

County	Projected Persons 65+ with Alzheimer's Disease				Prevalence Rate				Average Annual Growth Rate			
	2015	2020	2030	2040	2015	2020	2030	2040	2015-2020	2020-2030	2030-2040	2015-2040
Skamania	192	257	419	568	9.3%	9.5%	11.4%	15.4%	6.0%	5.0%	3.1%	4.4%
Snohomish	9,460	11,617	19,841	30,186	10.1%	9.6%	10.9%	14.0%	4.2%	5.5%	4.3%	4.8%
Spokane	7,949	9,188	14,209	19,165	10.7%	10.1%	11.8%	14.9%	2.9%	4.5%	3.0%	3.6%
Stevens	930	1,187	1,770	2,175	9.6%	10.0%	12.4%	15.7%	5.0%	4.1%	2.1%	3.5%
Thurston	4,200	5,131	8,167	11,166	10.2%	9.9%	11.9%	14.5%	4.1%	4.8%	3.2%	4.0%
Wahkiakum	128	163	233	244	9.5%	10.4%	14.3%	17.4%	4.8%	3.7%	0.5%	2.6%
Walla Walla	1,179	1,269	1,650	2,020	12.1%	11.5%	12.7%	15.7%	1.5%	2.7%	2.0%	2.2%
Whatcom	3,472	4,253	6,821	9,320	10.4%	10.1%	12.3%	15.0%	4.1%	4.8%	3.2%	4.0%
Whitman	544	627	882	1,109	11.2%	10.9%	12.3%	14.8%	2.9%	3.5%	2.3%	2.9%
Yakima	3,622	4,178	5,978	8,017	10.9%	10.7%	12.0%	14.4%	2.9%	3.6%	3.0%	3.2%
STATE	106,788	127,271	197,144	271,340	10.4%	10.1%	11.7%	14.5%	3.6%	4.5%	3.2%	3.8%

The totals for the State are the sum of the county-level projected numbers; they do not add up to the State projections presented earlier in the report due to rounding error and the use of additional county-level population projections. For the state-level projections, RDA used (1) the 2040 population forecast by age from WA OFM and (2) the national projections of persons with Alzheimer Disease by age from the study by Hebert et al. (Hebert LE, Weuve J, Scherr PA, Evans DA. Alzheimer disease in the United States (2010-2050) estimated using the 2010 Census. *Neurology* 2013;80:1778–83). From the Hebert’s study, RDA calculated Alzheimer Disease prevalence rates for ages 65 -74 years, 75 - 84 years, and 85+ years for years 2010 through 2040 in 5-year increments. Next, these national rates were applied to (multiplied by) the population forecast for WA for corresponding age groups and years.

For the county-level projections, RDA used the same approach and data sources, with an addition of (3) the county-level population projections by age for 2010-2040 from WA OFM. The age-specific national prevalence rates described above were applied to (multiplied by) county population aged 65 -74 years, 75 - 84 years, and 85+ years for years 2010 through 2040 in 5-year increments. RDA computed county-by-age group-by-year weights to adjust for small differences between the county-level population projections released by OFM in 2012 and the state-level population projections released in 2014.

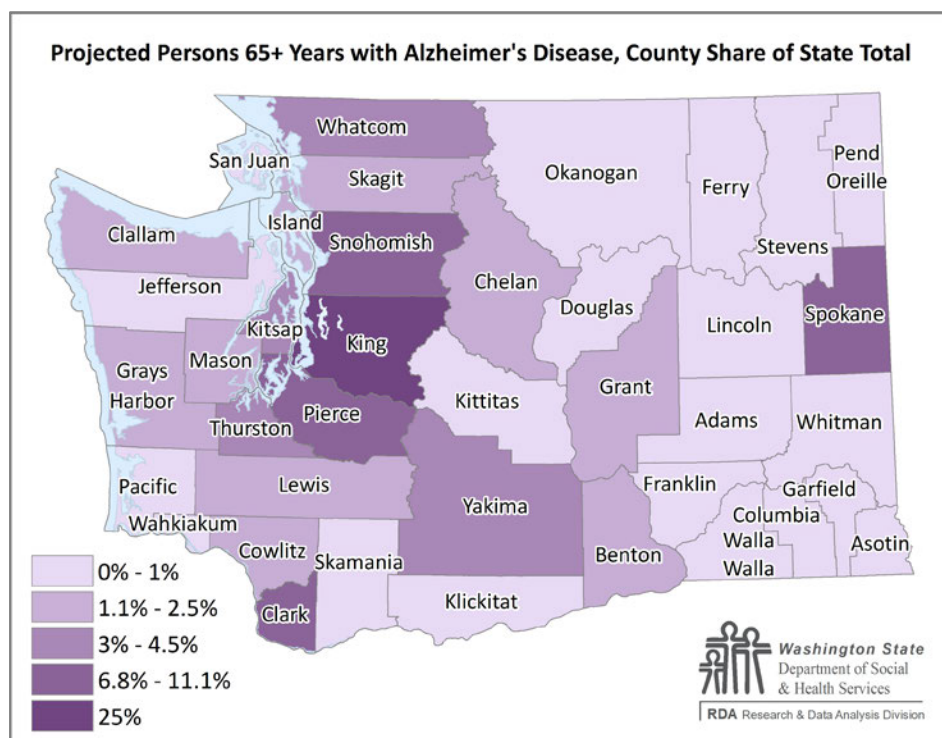


Figure 3. Projected persons with Alzheimer's, age 65+ as percent of state total.

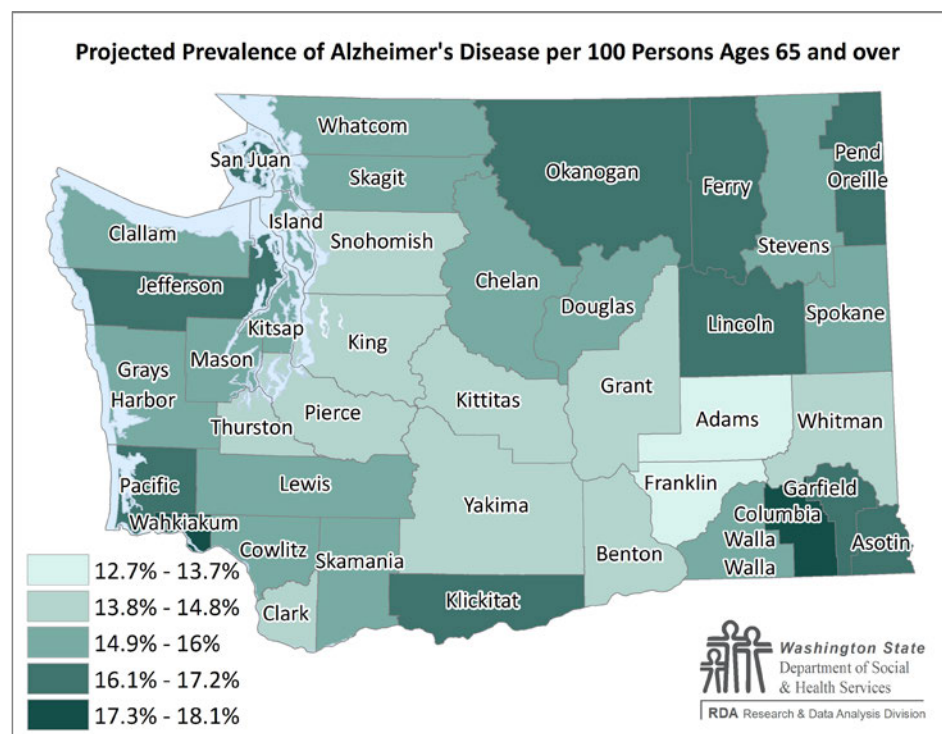


Figure 4. Projected prevalence of Alzheimer's per 100 persons 65+ years old.

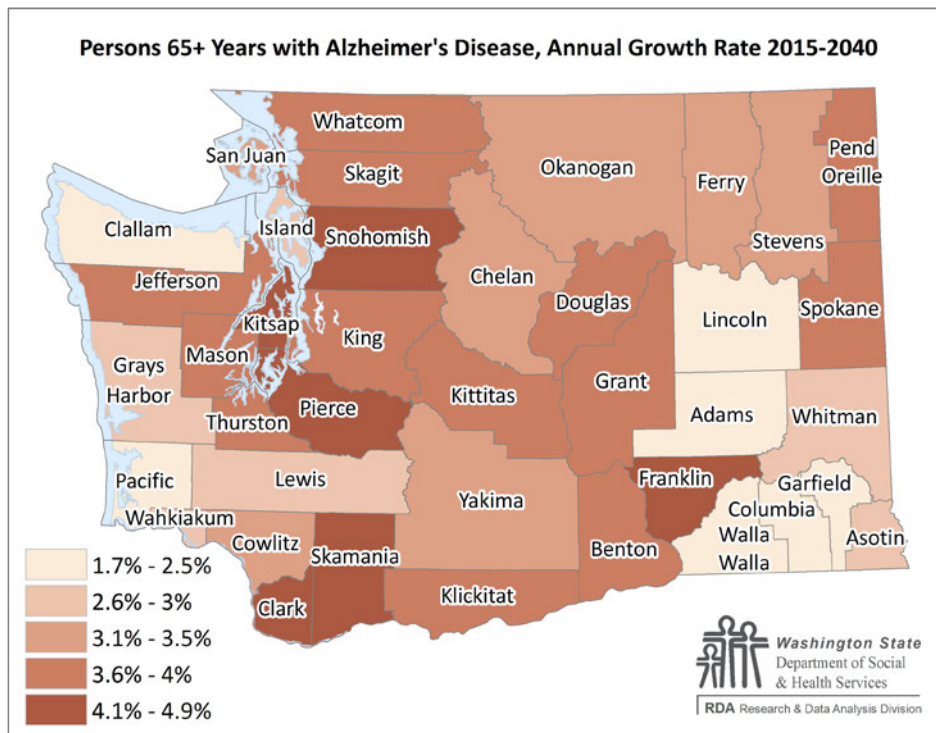


Figure 5. Projected persons with Alzheimer's annual growth rate.

GROWTH OF THE "OLDEST-OLD"

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 US. 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

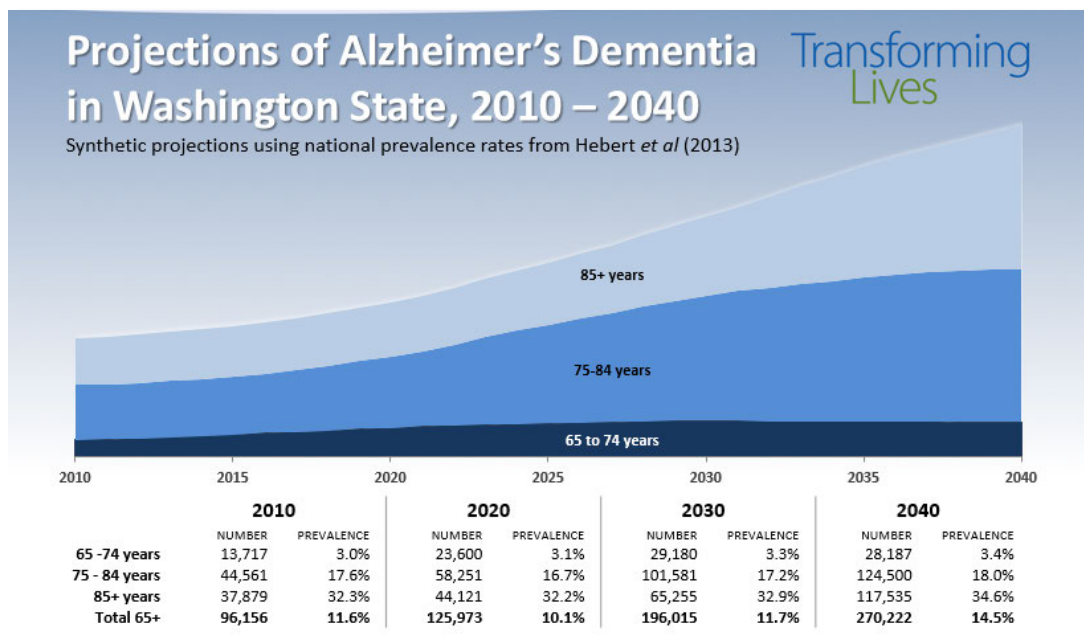


Figure 6. Projections of Alzheimer's disease in Washington State, 2010-2040. Data Sources: Total Population 65 and Over, by Age: Washington State Office of Financial Management, Forecasting and Research Division. Forecast of the State Population by Age.

LIVING ARRANGEMENTS

According to the Federal Interagency on Aging-Related Statistics, 19% of men over 65 live alone. Women over 65 were twice as likely as men to live alone (37% vs 19%). Living arrangements differed significantly by race and Hispanic origin, as shown in the chart below. Living arrangements have a significant impact on the need for long-term supports and services, including caregiver supports.

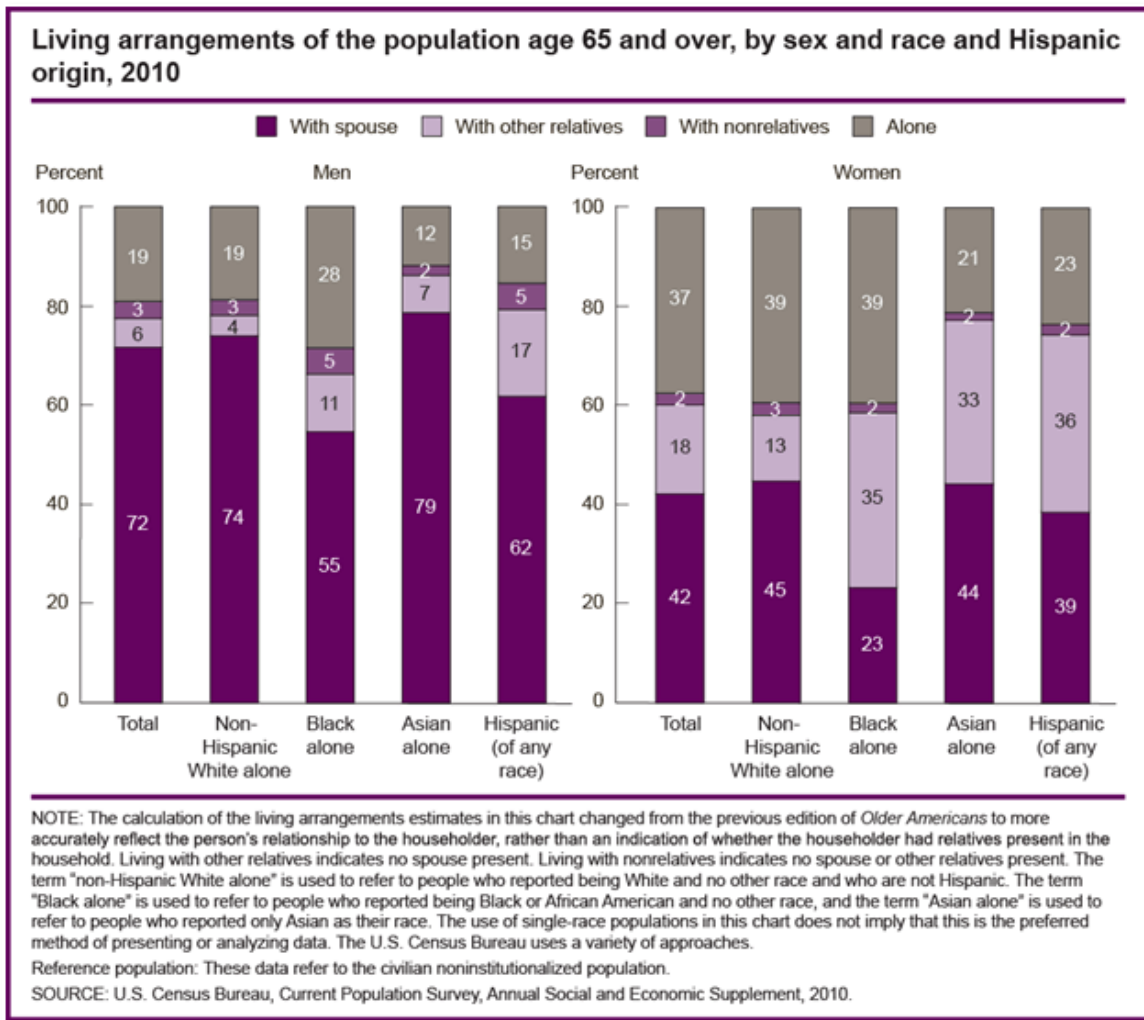


Figure 7. Living Arrangements of the population age 65 and over by sex, race and Hispanic origin.⁶

DEATH RATES FROM ALZHEIMER'S

While death rates for stroke and heart disease have generally declined over the past 10 years, the death rate for Alzheimer's is on the rise. In 2014, Washington State had the highest age-adjusted average annual death rate from Alzheimer's disease in the U.S at 44.1 per 100,000 people.⁷ 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 a comparison of the rate over time or to compare Washington with other states.

Table 2. Age-adjusted rates for 10 leading causes of death for Washington Residents, 2005-2014.

Mortality Table C1. Age-Adjusted Rates¹ for 10 Leading Causes of Death for Washington Residents, 2005-2014

Year	Heart Disease	Cancer	Strokes	COPD	Unintentional Injury	Alzheimer's	Diabetes	Flu & Pneumonia	Suicide	Liver Disease
2005	178.8	180.5	47.7	45.2	39.9	38.0	25.4	15.1	12.6	8.6
2006	167.4	175.1	43.3	43.4	40.7	39.1	24.6	12.8	12.1	8.8
2007	168.4	178.6	41.8	42.7	39.5	41.4	23.4	11.5	12.9	9.5
2008	162.6	175.1	41.9	45.5	40.3	46.6	24.1	11.7	13.0	9.7
2009	153.8	175.4	38.5	44.5	38.9	44.5	22.8	9.9	13.3	10.2
2010	150.5	170.0	36.7	40.3	37.3	43.6	21.6	8.2	13.8	10.4
2011	145.2	166.9	36.2	44.7	37.9	44.0	22.4	10.1	14.0	10.1
2012	140.4	162.9	34.7	41.4	38.4	44.2	22.7	9.9	14.6	11.2
2013	137.1	156.2	35.2	39.5	37.7	43.8	21.3	10.1	14.0	12.1
2014	138.3	157.0	34.7	38.3	40.4	44.1	21.4	9.4	15.4	11.2

¹Rate per 100,000 age-adjusted to U.S. 2000 population.

Source: Center for Health Statistics, Washington State Department of Health, 07/2015.

Washington State has the highest rate of death from Alzheimer's disease of any state. However, when comparing rates of death from all forms of dementia to the US, Washington falls in the middle of all US states. When someone dies, their literal cause of death from their death certificate is sent to the National Center for Health Statistics (NCHS) at CDC to be coded using ICD10. In general, the coded data is what is used by health researchers. Some codes, including dementia, are considered ill-defined and CDC would like each state to send follow-up letters to the medical certifiers of the cause of death asking for more information about the cause of death. This is called a query. The ability of states to query varies based on many factors and the level of querying is left up to each state. Washington State has a very active query program. It is not restricted to dementia, although dementia is a priority 1 level condition to query. The Department of Health attempts to send query letters to every medical certifier who writes "dementia" with no other explanation such as "Alzheimer's dementia", "Vascular dementia", "Dementia NOS", etc. asking them to specify the type of dementia. DOH does not replace the literals that the purchaser of a death certificate sees on the death certificate with this added information but they do update the cause of death literals that are sent to NCHS for ICD10 coding. Health researchers have access to both the original listed cause of death and the updated literals. In cases where an ill-defined cause of death is listed on the death certificate and the literal cause of death is updated in the data set, the changes do not require a correction affidavit. The process of querying and clarifying the detailed death data improves statistical analysis and may also be a reason why Washington leads the nation in age-adjusted death rates for Alzheimer's.

APPENDIX G: GLOSSARY

AARP – American Association of Retired Persons.

AD – Alzheimer’s disease. In this document, whenever Alzheimer’s is used, it is taken to mean Alzheimer’s and other dementias.

Adult Day Care – Adult day care includes programs, services, and facilities designed to assist physically or mentally impaired adults remain in their communities. These are persons who might otherwise require institutional or long-term care and rehabilitation. There are two general purposes for adult day-care. The first is to provide an alternative to placement in a residential institution. The second is to create a respite for caregivers, often the children of the persons for whom the care is being provided.

Adult Family Home (AFH) – A residential home in which a person or persons provide personal care, special care and room and board to more than one but not more than six adults who are not related by blood or marriage to the person or persons providing the services. Adult family homes may also be designated as a specialty home (on their license) in one or more of the following three categories: Developmental Disability, Mental Illness, and Dementia if they meet all certification and training requirements. See **Chapter 388-76 WAC** for more on adult family home licensing requirements.

Adult Protective Services (APS) – **APS** protects vulnerable adults by investigating allegations of abuse, neglect, abandonment, and financial exploitation when the person lives in their own home.

Adult Protective Services target population – A Vulnerable Adult is: any adult 60+ who cannot care for him or herself; or adults 18+ that have a legal guardian; have a developmental disability; live in a facility licensed by DSHS; 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. More on Adult Protect Services can be found at: www.adsa.dshs.wa.gov/APS

Aging and Disability Network Services – The National Aging Network (the Aging Network) was established in 1965 with the passage of the Older Americans Act and is one of the Nation’s largest provider networks of home and community-based care for older persons, adults with disabilities and their caregivers. The Administration on Aging, an agency in the U.S. Department of Health and Human Services, is a lead partner of the Aging Network which consists of 56 State Units on Aging, 629 Area Agencies on Aging, 246 Tribal organizations, 20,000 service providers, and thousands of volunteers.

Aging and Disability Resource Centers (ADRC) – The National Aging and Disability Resource Center Program, is a collaborative effort of the **Administration for Community Living**, the **Centers for Medicare & Medicaid Services**, and the **Veterans Health**

Administration. It is designed to streamline access to home and community supports and services for consumers of all ages, incomes and disabilities, and their families. Washington State has received federal grants to assist in the development, implementation, and statewide expansion of a sustainable system of fully functional Aging and Disability Resource Centers.

AGO – The Washington State **Office of the Attorney General**.

ALTSA – Aging and Long-Term Support Administration of the Department of Social and Health Services.

Alzheimer’s Association Care Navigation – Care Navigation provides a series of counseling appointments with a licensed social worker who is specifically trained in issues related to memory loss. Single appointments are also available. A Care Navigator can be a source of guidance, support, education, and empowerment as individuals and families navigate the challenges and changes associated with memory loss.

www.alzheimersnavigator.org

Alzheimer’s Cafes – An Alzheimer’s, dementia or memory café is a monthly gathering of individuals with memory loss along with their caregivers, and/or friends and family in a safe, supportive, and engaging environment. The cafe gives everyone a welcome break from the disease. **Alzheimer’s Cafes**

Alzheimer’s Disease Working Group (ADWG) – A group of people defined primarily through the **legislation** that created this Plan, who are charged with examining the array of needs of individuals diagnosed with Alzheimer’s disease and other dementias, services available to meet these needs, and the capacity of the state and current providers to meet these and future needs. The ADWG is also charged with identifying needed policies or responses including, but not limited to, the promotion of early detection and diagnosis of Alzheimer’s disease and dementia, the provision of coordinated services and supports to persons and families living with Alzheimer’s disease or dementia disorders, the capacity to meet these needs, and strategies to address identified gaps in services.

AD – Alzheimer’s and other dementias.

Area Agencies on Aging (AAA) – Local organizations that develop and promote services and options to maximize independence for elders, adults with disabilities, and family caregivers. Washington has thirteen Area Agencies on Aging that are comprised of county governments, regional councils, and tribes. A citizen advisory council guides the work. The **Washington Association of Area Agencies on Aging** is a membership organization made up of the 13 Area Agencies on Aging in Washington State that seeks to enhance the effectiveness of each AAA through a strong agenda of information, debate, advocacy and education.

Assisted Living Facility – a facility, 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** for more on assisted living licensing requirements.

Assistive Technologies – Assistive technology is any service or tool that helps the elderly or disabled do the activities they have always done but must now do differently. These tools are also sometimes called “adaptive devices.” (**U.S. Department of Health and Human Services**, Administration on Aging). Some examples include:

- Assistive listening devices
- Alert systems
- Medication Aids
- Identification Jewelry

Behavioral Risk Factor Surveillance System (BRFSS) – The Behavioral Risk Factor Surveillance System (BRFSS) is a United States health survey that looks at behavioral risk factors. It is run by Centers for Disease Control and Prevention and conducted by the individual state health departments. The survey is administered by telephone and is the world's largest such survey. In 2009, the BRFSS began conducting surveys by cellular phone in addition to traditional “landline” telephones. **Department of Health BRFSS**

Bree Collaborative – a group of public and private health care stakeholders working together to improve quality, health outcomes and cost effectiveness of care in Washington State. The group identifies up to three areas of health care services every year that have high variation in the way that care is delivered. Workgroup members identify and analyze evidence-based best practices to improve quality and reduce variation in practice patterns.

Care Transitions – refers to the movement patients make between health care practitioners and settings as their condition and care needs change during the course of a chronic or acute illness. Care Transition services are a set of actions designed to ensure the coordination and continuity of health care as patients transfer between different locations or different levels of care within the same location.

Centers for Disease Control and Prevention (CDC) – The CDC has a broad mission and vision, which includes tracking and aggregating health-related data and conducting critical population-based research, with the ultimate purpose of increasing the health security of the United States.

Centers for Medicare and Medicaid Services (CMS) – The **Centers for Medicare & Medicaid Services** is part of the US Department of Health and Human Services. CMS administers Medicare, Medicaid, the Children’s Health Insurance Program, and parts of the Affordable Care Act.

Chronic Disease Self-Management Program (CDSMP) – **CDSMP** is a peer-led workshop for people with one or more chronic diseases designed to help them manage their chronic disease better.

Community Living Connections – See Aging and Disability Resource Centers.

Community Options Program Entry System (COPES) Waiver – The COPES waiver was implemented in 1982 and is one of the oldest waivers in the nation. COPES services are funded with a combination of state dollars and with Title XIX (Medicaid) federal dollars. The Aging and Long-Term Support Administration partners with the Centers for Medicare and Medicaid Services and the Area Agencies on Aging to implement the COPES waiver.

COPES services are an effective alternative to nursing home placement and are an integral component of Washington State’s successful rebalancing of services from institutional to community-based settings.

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.

Dementia-friendly recreation – Dementia-Friendly Recreation provides meaningful recreation and social engagement opportunities for people living with memory loss throughout Seattle. (**Seattle Parks**)

DDA – Developmental Disabilities Administration of the Department of Social and Health Services.

DDC – Washington State Developmental Disabilities Council. The mission of the Washington State Developmental Disabilities Council is to work collaboratively with people with developmental disabilities, families and guardians, service providers, advocates and policy makers to assure that individuals with developmental disabilities and their families have access to culturally competent, consumer/family-centered supports and other assistance that promote independence, productivity, integration and inclusion into the community of their choice; and to promote this vision in the public policy and planning arena through system change, community capacity building and advocacy at the local, state and national level.

DOH – Washington State Department of Health.

DRW – Disability Rights Washington (DRW) is a private non-profit organization that protects the rights of people with disabilities statewide. Their mission is to advance the dignity, equality, and self-determination of people with disabilities. They work to pursue justice on matters related to human and legal rights.

DSHS – Washington State Department of Social and Health Services.

ED – Emergency department.

Evidence-Based Interventions – Evidence-based interventions (EBI) are treatments that have been proven effective (to some degree) through outcome evaluations. As such, EBI are treatments that are likely to be effective in changing target behavior if implemented with integrity. ([University of Missouri](#))

Family Caregiver Support Program – The Family Caregiver Support Program (FCSP) services unpaid family caregivers. It integrates an evidence-based caregiver assessment/consultation and care planning process known as TCARE® - Tailored Caregiver Assessment & Referral®.

The *Tailored Caregiver Assessment and Referral (TCARE®)* system was created by Rhonda Montgomery, PhD and colleagues at the University of Wisconsin-Milwaukee. The TCARE® protocol is designed to tailor services to the unique needs of each caregiver thereby reducing stress, depression and burdens associated with caregiving. TCARE® provides a consistent, objective and reliable screening and assessment process that identifies at-risk caregivers, targets resources to those most in need and determines whether support and services make a measurable difference to caregivers. TCARE® also helps inform policy through the collection of statewide data. The effectiveness of TCARE® is documented in published research articles based upon a national randomized control study, in which Washington State participated. For more information, visit the national TCARE® website at www.TCARE.uwm.edu.

The Family Caregiver Support Program is funded through federal (\$2,846,871) and state (\$11,242,000) funds (2015).

Gatekeeper programs – Local programs that train community members such as postal carriers, meter readers, bank tellers, pharmacy workers, ministers, etc. about identifying people who are experiencing or at risk of harm and how make referrals to existing services.

Geriatric Regional Assessment Team (GRAT) – A program in King County designed to provide crisis intervention services for older adults.

HCA – Washington State Health Care Authority. The Washington State Health Care Authority purchases health care for more than 2 million Washingtonians through two programs — Washington Apple Health (Medicaid) and the Public Employees Benefits Board (PEBB) Program. The HCA works with partners to help ensure Washingtonians have access to better health and better care at a lower cost.

Home and Community Services Division (HCS) – **HCS** promotes, plans, develops and provides long-term care services for persons with disabilities and the elderly who may need state funds (Medicaid) to help pay for them. The Home and Community Services

Division is part of the Aging and Long-Term Support Administration of Washington State Department of Social and Health Services.

Health Homes – The Affordable Care Act of 2010, Section 2703, created an optional Medicaid State Plan benefit for states to establish Health Homes to coordinate care for people with Medicaid who have chronic conditions by adding Section 1945 of the Social Security Act. CMS expects states health home providers to operate under a "whole-person" philosophy. Health Homes providers will integrate and coordinate all primary, acute, behavioral health, and long-term services and supports to treat the whole person. ([Medicaid.gov](https://www.medicaid.gov))

here:now program – here:now is an arts-engagement program for individuals living with dementia and their care partners to enjoy a creative and relaxing time together. The only museum-based arts program of its kind in Washington State, here:now offers gallery tours and art-making classes designed for individuals with young-onset or early to mid-stage dementia and their care partners. ([Frye Art Museum](https://www.fryemuseum.org))

Hospice Care – Hospice is a special type of care in which medical, psychological, and spiritual support are provided to patients and their loved ones when cancer therapies are no longer controlling the disease. Hospice care focuses on controlling pain and other symptoms of illness so patients can remain as comfortable as possible near the end of life. Hospice focuses on caring, not curing. The goal is to neither hasten nor postpone death. If the patient's condition improves or the cancer goes into remission, hospice care can be discontinued and active treatment may resume. Choosing hospice care doesn't mean giving up. It just means that the goal of treatment has changed.

The hospice team usually includes doctors, nurses, home health aides, social workers, clergy or other counselors, and trained volunteers. The team may also include speech, physical, and occupational therapists, if needed. A hospice team member is on-call 24 hours a day, 7 days a week to provide support. The hospice team will work with the patient on the patient's goals for end-of-life care, not a predetermined plan or scenario. Hospice care is very individualized.

Hospice services may include doctor or nursing care, medical supplies and equipment, home health aide services, short-term respite (relief) services for caregivers, drugs to help manage cancer-related symptoms, spiritual support and counseling, and social work services. Patients' families are also an important focus of hospice care, and services are designed to give them assistance and support.

Hospice care most often takes place at home. However, hospice care can also be delivered in special in-patient facilities, hospitals, and nursing homes. ([Source: NIH: National Cancer Institute](https://www.nationalcancerinstitute.gov))

Health Home Services – Health Home services are available to individuals with chronic illnesses and who are eligible for Medicaid or both Medicare and Medicaid. Individuals must also be at significant risk for health problems that can lead to unnecessary use of

hospitals, emergency rooms, and other expensive institutional settings such as psychiatric hospitals and nursing homes. Washington uses a predictive risk modeling system called PRISM to identify individuals who are at significant risk.

Individuals receiving Health Home services are assigned a Health Home coordinator who partners with beneficiaries, their families, doctors, and other agencies providing services to ensure coordination across these systems of care. The health home coordinator visits in-person and is also available by telephone to help the individual, their families, and service providers. For more information, go to:

www.hca.wa.gov/Pages/health_homes.aspx

Healthy Brain Research Network (HBRN) – A network of public health research facilities sponsored by the Centers for Disease Control which focuses on understanding cognitive changes over time, improving or maintaining cognitive function, and translate research into effective public health programs and practices. See also the **Healthy Brain Initiative**.

ICD-10 – The International Classification of Diseases, tenth edition. It is a coding system created by the World Health Organization. The U.S. National Center for Health Statistics (NCHS) and Centers for Medicare and Medicaid Services (CMS) use this as a foundation for a version (clinical modification) of ICD-10 that includes additional information.

LTC – Long-Term Care.

LTSS – Long-Term Supports and Services.

Memory Care & Wellness Services (MCWS) – A supervised daytime program for individuals with dementia and their family caregivers. Memory Care & Wellness Services (MCWS) offers a program that is a blend of health, social and family caregiver supports – it is defined and requirements are specified in the “Memory Care & Wellness Services Standards of Care, December 2010” (currently under refinement).

Memory Care & Wellness Services build upon the core services listed under Adult Day Care and add the following: A program day of five hours, offered two days per week; staffing that accommodates increasing functional and behavioral support needs of participants as they progress in their dementia, including: 1:4 (vs.1:6) staff to client ratio; and skilled nursing and/or therapy and social services available during program hours for the participant with targeted education and support of the family caregiver, as needed. A structured, specialized exercise program, *EnhanceMobility* is integrated into the program. Started through federal Alzheimer’s demonstration grants, this program has demonstrated that for individuals with dementia, quality of life improved and the frequency of behavior problems decreased. For family caregivers, distress over behavior problems decreased in participating caregivers while increasing in comparison group caregivers. Depressive symptoms, stress and burden also decreased.⁸

Memory Care and Wellness Services are currently available in 3 of 13 Area Agency on Aging (AAA) service areas. Original service areas (King County and Northwest WA AAAs) are now supporting MCWS through limited MCWS-funding within the Family Caregiver Support Program budget; a federal Pierce County demonstration grant will end Aug. 31, 2014 and may need additional funding to be sustained.

Natural Support Networks – “Natural Supports” means personal associations and relationships typically developed in the community that enhance the quality and security of life for people, including, but not limited to, family relationships; friendships reflecting the diversity of the neighborhood and the community; association with fellow students or employees in regular classrooms and work places; and associations developed through participation in clubs, organizations, and other civic activities. ([State of California](#))

NCHS – U.S. National Center for Health Statistics, www.cdc.gov/nchs/.

Nursing Facility Level of Care (NFLOC) criteria – The individual must: require care provided by or under the supervision of a registered nurse or a licensed practical nurse on a daily basis; have an unmet or partially met need with at least three ADLs as defined in WAC 388-106-0355; or have cognitive impairment and require supervision due to one or more of the following: disorientation, memory impairment, impaired decision-making, or wandering and have an unmet or partially met need with an ADL as defined in WAC 388-106-0355.

Office of Public Guardianship – The Office of Public Guardianship (OPG) operates provides guardians for people who Are incapable of caring for themselves and protecting their own interests; lack the funds to pay private guardians; and have no family or friends who can serve as volunteer guardians. The program stems from action taken during the 2007 legislative session, with the passage of Senate Bill (SB) 5320. This bill established the Office of Public Guardianship (OPG) within the Administrative Office of the Courts (AOC). The legislature appropriated funds for FY 08-09 to establish the OPG, to develop and implement pilot programs in a minimum of two areas, one urban and one rural. ([OPG](#))

Older Americans Act (OAA) – Although older individuals may receive services under many other Federal programs, today the [OAA](#) is considered to be the major vehicle for the organization and delivery of social and nutrition services to this group and their caregivers. The OAA is administered by the Administration on Aging. The [Washington State Senior Citizens Services Act](#) is the law that authorizes, administers and expands federal programs within our state.

Ombudsman – The Washington State Long-Term Care Ombudsman Program ([LTCOP](#)) advocates for residents of nursing homes, adult family homes, and assisted living facilities. Our purpose is to protect and promote the Resident Rights guaranteed these residents under Federal and State law and regulations.

Palliative Care – The World Health Organization defines palliative care as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care: provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patients illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Person Centered Care – an approach to care that respects and honors the unique qualities, interests, and needs of each person – it is not a one-size fits all approach to care. See www.ccal.org for more information.

Physician Orders for Life Sustaining Treatment (POLST) – A process by which a physician engages in end-of-life care decisions with an individual and documents the person's wishes and decisions related to end-of-life care. See www.polst.org.

Program to Encourage Active Rewarding Lives for Seniors (PEARLS) – PEARLS is a national evidence-based treatment program for depression in the elderly and for adults with epilepsy-related depression.

Reducing Disability in Alzheimer's Disease (RDAD) – RDAD is an evidence-based, in-home exercise program consisting of nine home visits by a specially-trained/certified RDAD "coach" over a six-week period.

RDAD research at the University of Washington demonstrated significant short and long-term benefits for people in the treatment group. Physical functioning improved and fewer participants ended up in nursing homes due to behavioral disturbances.

During the one-hour in-home sessions, the coach teaches easy-to-follow exercises to both the caregiver and care receiver (i.e. the person with dementia). The coach teaches the caregiver how to encourage and safely supervise the care receiver while doing the exercises. The coach also teaches caregivers how to handle some of the problems that occur with older adults who have memory problems or dementia.

RDAD is currently being translated through a National Institute on Aging grant (2012-17), with Washington (and Oregon) AAAs in the following Washington areas: Olympic, King County, Pierce, Snohomish, Southwest WA and Southeast WA. The federal grant is in operation from 2012-2017.

Residential Care Services (RCS) – RCS is responsible for the licensing and oversight of adult family homes, assisted living facilities, nursing facilities, intermediate care facilities for individuals with intellectual disabilities, and certified residential programs. Our mission is to promote and protect the rights, security and well-being of individuals living in these licensed or certified residential settings. RCS is a part of the Aging and Long-Term Support Administration of the Washington State Department of Social and Health Services.

Respite Care – Respite care services" means relief care for families or other caregivers of adults with functional disabilities, eligibility for which shall be determined by the department by rule. The services provide temporary care or supervision of adults with functional disabilities in substitution for the caregiver. The term includes adult day services. ([RCW 74.41.030](#))

Specialized Dementia Care Program (SDCP) – Initiated as a partnership with providers, stakeholders and the University of Washington (1999), the SDCP demonstrated the ability to accept and retain individuals with greater cognitive impairment and behavioral disturbances than traditional assisted living programs. For more information, see the University of Washington’s final outcome report on the [Dementia Care Pilot Project](#), 2003.

Participation in SDCP has shown to significantly delay nursing home placement. Based on the positive pilot project findings, 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](#).

SSB 6124 – [Substitute Senate Bill number 6124](#), which is legislation authorizing the formation of the ADWG and the development of the Washington Alzheimer’s State Plan.

STAR-C – STAR-C is an evidence-based dementia consultation program designed to help caregivers reduce or eliminate behaviors that are difficult to manage, such as anxiousness, resistance to care, wandering, or verbal or physical aggression.

This in-home education/consultation program, developed at the University of Washington, has shown to improve care receiver quality life, reduce the frequency of problem behaviors, and lower caregiving depression, burden, and distress over care receiver behavior changes. STAR-C is implemented in the caregivers’ homes by skilled consultants who are certified by the University of Washington to deliver STAR-C. It is now delivered over a six-week period, with 4 home visits and additional phone support.

STAR-C was first translated in Oregon through a federal demonstration grant and then modified into a condensed version in Oregon and Washington (2012-2014). It is now being continued in two service areas in Oregon and implemented in the following Washington areas: Central WA, King County, Lewis/Mason/Thurston AAA, Northwest WA, Southwest WA and Southeast WA.

UW – University of Washington.

WAC – Washington Administrative Code.

WINGS – Working Interdisciplinary Network of Guardianship Stakeholders, administered by the Washington State Supreme Court. WINGS serves to enhance the quality of care and life of adults affected or potentially affected by guardianship and other decision-making alternatives. WINGS is an ongoing problem-solving mechanism made up of key stakeholders. Four core goals include:

- Identify strengths and weaknesses in the state’s current approach to adult guardianship and less restrictive decision-making options;
- Address key policy and practice issues;
- Engage in outreach, education and training, including, for example, training on supported decision-making; and
- Serve as an ongoing problem-solving mechanism to enhance the quality of care and quality of life of adults affected or potentially affected by guardianship and other decision-making alternatives, and provide the support they need.

APPENDIX H: REFERENCES

- Adult Family Home Quality Assurance Panel. (2012). *Adult Family Home Quality Assurance Panel Report: Recommendations to the Governor and Legislature per ESHB 1277*. Olympia, WA.
- Alzheimer's Association. (2011). 2011 Alzheimer's Disease Facts and Figures. *Alzheimer's & Dementia*, 7(2). Retrieved from [http://www.alzheimersanddementia.com/article/S1552-5260\(11\)00036-7/pdf](http://www.alzheimersanddementia.com/article/S1552-5260(11)00036-7/pdf)
- Alzheimer's Association. (2012). 2012 Alzheimer's Disease Facts and Figures. *Alzheimer's & Dementia*, 8(2). Retrieved from [http://www.alzheimersanddementia.com/article/S1552-5260\(12\)00032-5/pdf](http://www.alzheimersanddementia.com/article/S1552-5260(12)00032-5/pdf)
- Alzheimer's Association. (2015). 2015 Alzheimer's Disease Facts and figures. *Alzheimer's & Dementia*, 11(3), p. 332+. Retrieved from [http://www.alzheimersanddementia.com/article/S1552-5260\(15\)00058-8/pdf](http://www.alzheimersanddementia.com/article/S1552-5260(15)00058-8/pdf)
- Alzheimer's Association and Centers for Disease Control and Prevention. (2013). *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018*. Chicago, IL. Retrieved from The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013–2018
- Anderson, L. A., Day, K. L., Beard, R. L., Reed, P. S., & Wu, B. (2009). The public's perceptions about cognitive health and Alzheimer's disease among the U.S. population: a national review. *Gerontologist*, 49(S1), S3-11. Retrieved from <http://gerontologist.oxfordjournals.org/content/49/S1/S3.full.pdf+html?sid=42d07449-ce14-4154-8dd2-70c519616bb8>
- Assistant Secretary for Planning and Evaluation. (2015). *National Plan to Address Alzheimer's Disease: 2015 Update*. Washington, DC: US Department of Health and Human Services. Retrieved from <http://aspe.hhs.gov/pdf-document/national-plan-address-alzheimer%E2%80%99s-disease-2015-update>
- Borson, S., & Chodosh, J. (2014). Developing dementia-capable health care systems: A 12-step program. *Clinics in Geriatric Medicine*, 395-420. Retrieved from <http://dx.doi.org/10.1016/j.cger.2014.05.001>
- Bradford, A., Kunik, M. E., Shultz, P., Williams, S. P., & Singh, H. (2009). Missed and delayed diagnosis of dementia in primary care: prevalence and contributing factors. *Alzheimer Disease and Associated Disorders*, 23(4), 306.
- Burley, M. (2011). *Inpatient Psychiatric Capacity in Washington State: Assessing Future Needs and Impacts*. Olympia, WA: Washington State Institute for Public Policy. doi:11-10-3401

- Cascioli, T., Al-Madfai, H., Osborne, P., & Phelps, S. (2008). An evaluation of the needs and service usage of family carers of people with dementia. *Quality in Ageing and Older Adults*, 9(2), 18-27. doi:10.1108/14717794200800011
- Center of Excellence on Elder Abuse and Neglect. (n.d.). *How at risk for abuse are people with dementia?* Retrieved August 2015, from Center of Excellence on Elder Abuse and Neglect:
http://www.centeronelderabuse.org/docs/PwDementia_Factsheet.pdf
- Centers for Disease Control and Prevention. (2015). *Stats of the State of Washington*. Retrieved from Centers for Disease Control and Prevention:
http://www.cdc.gov/nchs/pressroom/states/WA_2015.pdf
- DSHS RDA. (2015). *Estimated number and percentage of elders with Alzheimer's disease or dementia residing in rural areas of the state*. Research and Data Analysis Division. Olympia, WA: Department of Social and Health Services.
- Family Caregiver Alliance. (2003, May). *Women and caregiving: facts and figures*. Retrieved from Family Caregiver Alliance, National Center on Caregiving:
<https://caregiver.org/women-and-caregiving-facts-and-figures>
- Federal Interagency Forum on Aging-Related Statistics. (2011). *Population Data*. Retrieved from AgingStats.gov:
http://www.agingstats.gov/main_site/data/2012_documents/population.aspx
- Genworth. (2015). *Genworth 2015 Cost of Care Survey: Home Care Providers, Adult Day Health Care Facilities, Assisted Living Facilities and Nursing Homes*. Richmond, VA: Genworth Financial, Inc. Retrieved from
https://www.genworth.com/dam/Americas/US/PDFs/Consumer/corporate/130568_040115_gnw.pdf
- Hebert, L. E., Weuve, J., Scherr, P. A., & Evans, D. A. (2013). Alzheimer disease in the United States (2010-2050) estimated using the 2010 census. *Neurology*, 80(19), 1778-1783. Retrieved from
<http://www.neurology.org/content/80/19/1778.short>
- Hunt, G. G., Johnson, J., Maus, C., & Murphy, M. B. (2006). *Caregiving in Rural America*. Easter Seals Disability Services and the National Alliance for Caregiving. Retrieved from http://www.caregiving.org/wp-content/uploads/2014/01/Easter-Seals_NAC_Caregiving_in_Rural.pdf
- Hurd, M. D., Martorell, P., Delavande, A., Mullen, K. J., & Langa, K. M. (2013). Monetary costs of dementia in the United States. *New England Journal of Medicine*, 368(14), 1326-1334. Retrieved from
<http://www.nejm.org/doi/full/10.1056/nejmsa1204629>

- Katsuno, T. (2005). Dementia from the inside: how people with early-stage dementia evaluate their quality of life. *Ageing and Society*, 25(2), 197-214.
doi:10.1017/S0144686X0400279X
- Kohlenber, L., Raiha, N., & Felver, B. (2014). *What do older adults and people with disabilities need?* Research and Data Analysis Division. Olympia, WA: Washington Department of Social and Health Services, Aging and Disabilities Services Administration.
- Lavelle, B., Mancuso, D., Huber, A., & Felver, B. E. (2014). *Expanding eligibility for the Family Caregiver Support Program in SFY 2012*. Olympia, WA: Washington Department of Social and Health Services. Retrieved from <https://www.dshs.wa.gov/sites/default/files/SESA/rda/documents/research-8-31.pdf>
- Lin, S.-Y., Becker, M., & Belza, B. (2014). From dementia fearful to dementia friendly: be a champion in your community. *Journal of Gerontological Nursing*, 40(12), 3.
- Logsdon, R. G., Pike, K. C., Korte, L., & Goehring, C. (2014). Memory care and wellness services: Efficacy of specialized dementia care in adult day services. *Gerontologist*. doi:10.1093/geront/gnu012
- Marist Institute for Public Opinion. (2012). *Alzheimer's Public Opinion Survey*. Poughkeepsie, NY: Home Instead Senior Care. Retrieved from <http://maristpoll.marist.edu/1114-alzheimers-most-feared-disease/>
- National Institute on Aging. (2012). *Preventing Alzheimer's disease: What do we know?* National Institutes of Health, US Department of Health and Human Services. Retrieved from <https://www.nia.nih.gov/alzheimers/publication/preventing-alzheimers-disease/introduction>
- National Institute on Aging. (2012, September). *Risk factors for Alzheimer's disease*. Retrieved from Preventing Alzheimer's disease: what do we know?: <https://www.nia.nih.gov/alzheimers/publication/preventing-alzheimers-disease/risk-factors-alzheimers-disease>
- Okura, T., Plassman, B. L., Steffens, D. C., Llewellyn, D. J., Potter, G. G., & Langa, K. M. (2011). Neuropsychiatric symptoms and the risk of institutionalization and death: the aging, demographics, and memory study. *Journal of the American Geriatrics Society*, 59(3), 473-481.
- Phelan, E., Borson, S., Grothaus, L., Balch, S., & Larson, E. B. (2012). Association of Incident dementia with Hospitalization. *Journal of the American Medical Association*, 165-172.

- Plassman, B. L., Langa, K., Fisher, G. G., Heeringa, S. G., Weir, D. R., Ofstedal, M. B., & Wallace, R. B. (2007). Prevalence of dementia in the United States: the aging, demographics and memory study. *Neuroepidemiology*, 29(1-2), 125-132.
- Race, Ethnicity and Alzheimer's Disease*. (2013, April). Retrieved from Alzheimer's and Public Health Spotlight: http://alz.org/documents_custom/public-health/spotlight-race-ethnicity.pdf
- Reinhard, S. C., Kassner, E., Houser, A., Ujvari, K., Mollica, R., & Hendrickson, L. (2014). Raising Expectations 2014: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers. *Public Policy Institute*. Retrieved from <http://www.aarp.org/home-family/caregiving/info-2014/raising-expectations-2014-AARP-ppi-health.html>
- Shih, R. A., Concannon, T. W., Liu, J. L., & Friedman, E. M. (2014). *Improving Dementia Long-Term Care: A Policy Blueprint*. Santa Monica, CA: Rand Corporation. Retrieved from http://www.rand.org/content/dam/rand/pubs/research_reports/RR500/RR597/RAND_RR597.pdf
- SPADO. (2012). *State Plan for Alzheimer's Disease and Related Dementias in Oregon*. Salem, Oregon: State of Oregon. Retrieved from http://www.alz.org/oregon/documents/spado_report.pdf
- Stark, S. L., Roe, C. M., Grant, E. A., Hollingsworth, H., Benzinger, T. L., Fagan, A. M., . . . Morris, J. C. (2013). Preclinical Alzheimer disease and risk of falls. *Neurology*, 81(5), 437-443.
- The Dr. Robert Bree Collaborative. (November 2014). *End-of-Life Care Report and Recommendations*. Olympia, WA: Foundation for Health Care Quality. Retrieved from <http://www.breecollaborative.org/topic-areas/eol/>
- Tommis, Y., Seddon, D., Woods, B., Robinson, C. A., Reeves, C., & Russell, I. T. (2007). Rural-urban differences in the effects on mental well-being of caring for people with stroke or dementia. *Aging and Mental Health*, 11(6), 743-750. doi:10.1080/13607860701365972
- US Census Bureau. (n.d.). Washington State Prevalence of Serious Cognitive Difficulty for Persons 65+, by Age: US Census Bureau. 2013 American Community Survey 1-Year PUMS files. Retrieved November 3, 2014, from http://www.census.gov/acs/www/data_documentation/data_ferrett_for_pums/
- US Government Accountability Office. (2015). *Antipsychotic Drug Use: HHS has Initiatives to Reduce Use Among Older Adults in Nursing Homes, but Should Expand Efforts to Other Settings*. Washington, DC: United States Government Accountability Office. Retrieved from <http://www.gao.gov/assets/670/668221.pdf>

- WA Department of Health. (2007). *Data Systems*. Retrieved from Behavioral Risk Factor Surveillance System (BRFSS):
<http://www.doh.wa.gov/DataandStatisticalReports/DataSystems/BehavioralRiskFactorSurveillanceSystemBRFSS>
- Washington Office of Financial Management. (2012, August). County Growth Management Population Projections by Age and Sex: 2010 - 2040, 2012 Projections. Olympia, WA. Retrieved from
http://www.ofm.wa.gov/pop/gma/projections12/GMA_2012_county_pop_projections.pdf
- Washington State Department of Health. (2014). *Death Tables by Year*. Retrieved from Vital Statistics and Population Data:
<http://www.doh.wa.gov/DataandStatisticalReports/VitalStatisticsandPopulationData/Death/DeathTablesbyYear>
- Washington State Office of Financial Management. (2013). *Forecast of the State Population by Age and Sex, 2010-2040*. Forecasting and Research Division, Olympia, WA.
- Wei, R., Anderson, R. N., Curtin, L. R., & Arias, E. (2012, September 14). U.S. Decennial Life Tables for 1999-2001: State Life Tables. *National Vital Statistics Reports*, 60(9). Retrieved from
[http://www.cdc.gov/nchs/data/nvsr/nvsr60/nvsr60_09.pdf#x2013;2001:%20State%20Life%20Tables%20\[PDF%20-%201%20MB\]</a](http://www.cdc.gov/nchs/data/nvsr/nvsr60/nvsr60_09.pdf#x2013;2001:%20State%20Life%20Tables%20[PDF%20-%201%20MB]</a)
- Weiner, M., Friedl, K. E., Pacifico, A., Chapman, J. C., Jaffee, M. S., Little, D. M., . . . Zetterberg, C. M. (2013, July). Military Risk Factors for Alzheimer's Disease. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 9(4), 445-451. Retrieved September 2015, from
[http://www.alzheimersanddementia.com/article/S1552-5260\(13\)00132-5/fulltext](http://www.alzheimersanddementia.com/article/S1552-5260(13)00132-5/fulltext)
- Yaffe, K., Vittinghoff, E., Lindquist, K., Barnes, D., Covinsky, K. E., Neylan, T., . . . Marmar, C. (2010). Posttraumatic Stress Disorder and Risk of Dementia Among US Veterans. *Arch Gen Psychiatry*, 67(6), 608-613. Retrieved September 2015, from
<http://archpsyc.jamanetwork.com/article.aspx?articleid=210821>
- Zhao, Y., Kuo, T.-C. W., Kramer, M. S., & Ash, A. S. (2008). Healthcare costs and utilization for Medicare beneficiaries with Alzheimer's. *BMC Health Services Research*. Retrieved from
<http://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-8-108>

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- ¹ (Plassman, et al., 2007)
- ² (Alzheimer's Association and Centers for Disease Control and Prevention, 2013)
- ³ (Hebert, Weuve, Scherr, & Evans, 2013)
- ⁴ (National Institute on Aging, 2012)
- ⁵ (Plassman, et al., 2007)
- ⁶ (Alzheimer's Association, 2012)
- ⁷ (Wei, Anderson, Curtin, & Arias, 2012)
- ⁸ (Hebert, Weuve, Scherr, & Evans, 2013)
- ⁹ (Washington State Office of Financial Management, 2013)
- ¹⁰ (Plassman, et al., 2007)
- ¹¹ (Washington State Department of Health, 2014)
- ¹² (Washington State Department of Health, 2014)
- ¹³ (Stark, et al., 2013)
- ¹⁴ (Alzheimer's Association, 2012)
- ¹⁵ (Okura, et al., 2011)
- ¹⁶ (Alzheimer's Association, 2011)
- ¹⁷ (Alzheimer's Association, 2015)
- ¹⁸ (Alzheimer's Association, 2015), (DSHS RDA, 2015)
- ¹⁹ (WA Department of Health, 2007)
- ²⁰ (Family Caregiver Alliance, 2003)
- ²¹ (Alzheimer's Association, 2015)
- ²² (Alzheimer's Association, 2015)
- ²³ (Reinhard, et al., 2014)
- ²⁴ (Reinhard, et al., 2014)
- ²⁵ (SPADO, 2012)
- ²⁶ (SPADO, 2012)
- ²⁷ (Race, Ethnicity and Alzheimer's Disease, 2013)
- ²⁸ (DSHS RDA, 2015)
- ²⁹ (Hunt, Johnson, Maus, & Murphy, 2006)
- ³⁰ (Cascoli, Al-Madfai, Osborne, & Phelps, 2008), (Tommis, et al., 2007)
- ³¹ (Cascoli, Al-Madfai, Osborne, & Phelps, 2008)
- ³² (Hurd, Martorell, Delavande, Mullen, & Langa, 2013)
- ³³ (Shih, Concannon, Liu, & Friedman, 2014)
- ³⁴ (Alzheimer's Association, 2015)
- ³⁵ (Alzheimer's Association, 2015)
- ³⁶ (Alzheimer's Association, 2015)
- ³⁷ (Alzheimer's Association, 2015)
- ³⁸ (Alzheimer's Association, 2015)
- ³⁹ (Alzheimer's Association, 2015)
- ⁴⁰ (Alzheimer's Association, 2015)
- ⁴¹ (Alzheimer's Association, 2015)
- ⁴² Based upon model developed by Michael Splaine of Splaine Consulting.
- ⁴³ (Shih, Concannon, Liu, & Friedman, 2014)
- ⁴⁴ (Yaffe, et al., 2010)
- ⁴⁵ (Weiner, et al., 2013)
- ⁴⁶ (National Institute on Aging, 2012)
- ⁴⁷ (Lin, Becker, & Belza, 2014)
- ⁴⁸ Healthy People 2020 objectives include (1) increasing the proportion with diagnosed AD/dementia that are aware of the diagnosis; and (2) reducing the proportion of preventable hospitalizations in person with AD and other dementia.

⁴⁹ Ensure the sample size is large enough to establish statewide estimates, which may require oversampling some populations. The Workgroup recommends that necessary data be collected by the Behavioral Risk Factor Surveillance System (BRFSS) survey administered by the Washington State Department of Health beginning with the 2016 survey. Toward that end, sufficient funds should be allocated to administer BRFSS cognitive and caregiver modules as State-Added Questions. Furthermore, funding should be allocated to recruit additional survey participants above the typical Washington State BRFSS sample of approximately 14,000 persons. This oversampling is necessary to obtain a sufficient number of completed questionnaires to produce meaningful data about individuals with Alzheimer's disease, dementia or other forms of memory loss and their caregivers.

⁵⁰ (Center of Excellence on Elder Abuse and Neglect)

⁵¹ (Assistant Secretary for Planning and Evaluation, 2015)

⁵² (Lavelle, Mancuso, Huber, & Felver, 2014)

⁵³ (Bradford, Kunik, Shultz, Williams, & Singh, 2009)

⁵⁴ (Alzheimer's Association and Centers for Disease Control and Prevention, 2013)

⁵⁵ (Phelan, Borson, Grothaus, Balch, & Larson, 2012)

⁵⁶ (Borson & Chodosh, 2014)

⁵⁷ Opportunities for integration might be Healthier Washington Practice Transformation, Health Homes, Transition of care Initiatives and collaborative care models.

⁵⁸ Foundational knowledge could include: 1) Identify signs and symptoms of cognitive impairment or dementia; 2) Involve the care partner early; 3) Make a diagnosis of cognitive impairment or dementia or refer to someone who can make the diagnosis; 4) Manage the medically indicated interventions or refer to someone who can; and 5) Provide tools/support to the care partner.

⁵⁹ Performance metrics could include Physician Quality Reporting System (PQRS) endorsed metrics or Association of Neurology recommended metrics (at minimum a measure for clinic-based dementia screening).

⁶⁰ Examples include poor control of blood pressure and blood sugar with concurrent irritability, mood lability and exacerbation of cognitive symptoms, inability to understand or follow directions or follow through or engage in effective self-management.

⁶¹ (Borson & Chodosh, 2014)

⁶² Develop new and support existing care coordination efforts (e.g., Health Homes, Home Health visits, SNF transitions of care initiative, WSHA safe table on transitions, Coleman Transitions (CTI), and Qualis Health communities for safe transitions resources) - to improve outcomes related to ED Visits, hospitalizations and readmissions through improved transitions of care from hospital to community (i.e. models such as Indiana University's Center's Healthy Aging Brain Center's team-based collaborative care model).

⁶³ Resources such as the Alzheimer's Association, STAR-C behavior intervention, Alzheimer's Reading Room, etc.

⁶⁴ (Kohlenber, Raiha, & Felver, 2014)

⁶⁵ (Genworth, 2015)

⁶⁶ (Reinhard, et al., 2014)

⁶⁷ (Logsdon, Pike, Korte, & Goehring, 2014)

⁶⁸ See: http://www.aoa.acl.gov/AoA_Programs/HPW/Alz_Grants/star-c.aspx

⁶⁹ DSHS Comprehensive Assessment Reporting Evaluation (CARE), 2015. CARE is the tool used by case managers to document a client's functional ability, determine eligibility for long-term care services, evaluate what and how much assistance a client will receive, and develop a plan of care.

⁷⁰ (Adult Family Home Quality Assurance Panel, 2012)

⁷¹ (Burley, 2011)

⁷² (National Institute on Aging, 2012)

⁷³ (Plassman, et al., 2007)


⁷⁴ (Hebert, Weuve, Scherr, & Evans, 2013)

⁷⁵ (Plassman, et al., 2007), (Hebert, Weuve, Scherr, & Evans, 2013), (Washington State Office of Financial Management, 2013)

⁷⁶ (Alzheimer's Association, 2015)

⁷⁷ (Federal Interagency Forum on Aging-Related Statistics, 2011)

⁷⁸ (Centers for Disease Control and Prevention, 2015)



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

