

# Inventory of Supports and Services for People with Alzheimer's Disease and Related Dementias in Washington State

## Background

**Alzheimer's disease** is a progressive, irreversible, disease of the brain. It leads to cognitive impairment including memory loss and declining abilities to carry on a conversation, reason, and solve problems. Over time, cognitive changes also result in a diminishing capacity to perform activities of daily living and can lead to behavioral and psychological symptoms such as anxiety, depression, delusions, hallucinations, and agitation. In this brief, "Alzheimer's disease" also refers to other related dementias including vascular, Lewy body, mixed, and frontotemporal.

**In Washington State, an estimated 110,000 individuals have Alzheimer's disease or a related dementia. By 2025, this is projected to be 150,000.<sup>1</sup>**

Alzheimer's disease is a significant public health issue.

Unless an approach to prevent or effectively treat it is found, the number of people with Alzheimer's disease will increase significantly in the next twenty years. In Washington State, an estimated 110,000 individuals have Alzheimer's disease or a related form of dementia. By 2025, this number is projected to increase to 150,000.<sup>1</sup>

Currently, there is no known prevention or cure for Alzheimer's disease. Five medications are approved by the U.S. Food and Drug Administration that temporarily improve symptoms of Alzheimer's disease. The effectiveness of these medications differs among populations. Studies show that providing "active medical management" of Alzheimer's disease and other dementias can improve quality of life through all stages of the disease for individuals with dementia and their caregivers.<sup>2,3,4</sup> Active management is defined as "the appropriate use of available treatment options; effective management of coexisting conditions; coordination of care among physicians, other health care professionals and lay caregivers; participation in activities and/or adult day care programs; and taking part in support groups and supportive services."<sup>1</sup>

Alzheimer's disease impacts the entire family. It is well documented that Alzheimer's disease places physical and emotional strain on individuals and families. Family members caring for loved ones with dementia exhibit significant levels of depression and burden. Studies indicate people age 65 and older live an average of four to eight years after receiving the diagnosis of Alzheimer's disease. This duration of illness means families face increasing demands over relatively long periods of time. National statistics reveal 43% of caregivers of people with Alzheimer's disease provide care for one to four years compared with 33% of caregivers of individuals without dementia.<sup>5</sup>

Individuals with dementia and their caregivers can access information and supportive services through private organizations such as the **Alzheimer's Association Western and Central Washington Chapter**, the **Alzheimer's Association Inland Northwest Chapter** or the **Alzheimer Society of Washington**. Because of increasing care needs over the progression of the illness, many individuals and families turn to long-term services provided by state and federal public funding such as Medicaid and Older Americans Act.

Washington State's Department of Social and Health Services, Aging and Long-Term Support Administration has developed a statewide network of home and community-based services. Resources support adults living at home who need information and services to assist with chronic care needs or disabilities and adults who are no longer able to live at home but want to live in a residential setting.

Adults with memory issues and/or diagnosed dementia are served in programs and settings throughout the long-term services and supports system. This has prompted, over time, the development of dementia-informed policies (e.g. COPES eligibility) and some dementia-specific services targeted to the particular needs of the population (e.g. Memory Care & Wellness Services, STAR-C, and the Specialized Dementia Care Program in Assisted Living Facilities). Other services, while not dementia-specific, assist a substantial number of people living with memory loss/dementia (e.g. Information & Assistance/Aging & Disability Resource Centers, case management, personal care providers).

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. This inventory is arranged in the following sections:

- Services available through the Aging & Disability Network, a network of community-based services funded by local, state and the federal Older Americans Act funding.
- Dementia-specific services are presented first; general services for this population follow in alphabetical order.
- Medicaid State Plan and Medicaid Waiver Services. Dementia-specific services are presented first; general services for this population follow in alphabetical order.

## Services Available through Aging and Long-Term Support Administration

**Aging & Disability Network Services** – Area Agencies on Aging provide a network of community-based services funded by local, state and the federal Older Americans Act funding.

Service/ Program	Target population	Description/Limitations
<b>Memory Care &amp; Wellness Services</b>	<p>Unpaid family caregivers who care for a person with a diagnosis of Alzheimer's disease or other dementia (care receiver).</p> <p>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 <u>or</u> 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).</p>	<p>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>.</p> <p>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.<sup>8</sup></p> <p>Availability: The Memory Care &amp; Wellness Services program is available with 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 will end Aug. 31, 2014 and may need additional funding to sustain.</p>
<b>Reducing Disability in Alzheimer's Disease</b>	<p>Individuals with Alzheimer's disease or other dementia with an available family caregiver to assist.</p>	<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.<sup>9,10</sup></p> <p>Availability: The Reducing Disability in Alzheimer's</p>

		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.)
<b>STAR-C Dementia Consultation (focus on Behavioral Problem-Solving)</b>	<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, depression, etc. (See more on TCARE® in the Appendix under the FCSP).</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.<sup>11,12</sup></p> <p><u>Availability:</u> STAR-C Dementia Consultation is available in six Area Agencies on Aging. It is a pilot project funded through Older Americans Act Title III administrative funds. Funding is used by AAAs along with FCSP funds for direct services. Further expansion would require additional infrastructure funding.</p>
<b>Adult Protective Services</b>	<p>Any adult 60+ who cannot care for him or herself; or adults 18+ that have a legal guardian; have a documented developmental disability, etc. (see full definition of target population/eligibility in Appendix).</p> <p>Individuals with dementia or other cognitive impairments are thought to be at greater risk of abuse and neglect than those of the general older adult population.</p>	<p>Adult Protective Services receives and investigates allegations of abuse (physical, mental, sexual, and exploitation), abandonment, neglect, self-neglect, and financial exploitation of vulnerable adults living in their own homes and in facilities where there is an allegation of mistreatment by someone outside of the facility.</p> <p>Adult Protect Services are available statewide to individuals of all income levels.</p> <p>To report suspected abuse or neglect of a vulnerable adult or child: <b>Call 1-866-ENDHARM (1-866-363-4276)</b></p>
<b>Aging and Disability Resource Centers and Information &amp; Assistance</b>	<p>Older adults (60+) or individuals with disabilities (18+) and/or their family/caregivers.</p> <p>While not dementia-specific, both programs serve individuals and families living with memory loss/dementia.</p>	<p>These programs provide individuals and families living with dementia a local access point to call for information, services, and resources. Aging and Disability Resource Centers offer person-centered options counseling. (See additional program descriptions in the appendix.)</p> <p>Information &amp; Assistance is available statewide for older adults and individuals who are helping older adults. Aging and Disability Resource Centers, designed to serve all ages, are operating in four Area Agencies on Aging, with plans to expand statewide by 2015 pending available funding.</p>

<b>Aging &amp; Disability Network Services (In-Home Services)</b>	<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 &amp; 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>Available statewide through the 13 Area Agencies on Aging.</p>
<b>Care Transitions</b>	<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 &amp; Disability Resource Center</i> project is concentrated on patient-centered hospital-to-home care transitions using an evidence-based coaching model, Care Transition Intervention<sup>®</sup>, developed by Eric Coleman and his team at the University of Colorado at Denver.</p> <p>11 of 13 AAAs have trained coaches. (See Appendix for more information.)</p>
<b>Family Caregiver Support Program</b>	<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 55% of care receivers have either a probable or firm diagnosis of Alzheimer's disease/dementia; another 31% are suspected to have memory or cognitive problems (2012).</p>	<p>The Family Caregiver Support Program (FCSP) offers an evidence-based caregiver assessment/consultation and care planning process (TCARE<sup>®</sup>) 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 available statewide.</p>

**Medicaid State Plan and Medicaid Waiver Services** - Recent estimates indicate 11% of in-home clients, 27% of Assisted Living Facility clients and 37% of Adult Family Home clients have a diagnosis of Alzheimer's disease or other dementia identified in the state's functional assessment system (The CARE Tool).

Service/ Program	Target population	Description/Limitations
<b>Dementia Specialty Training</b>	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>
<b>Specialized Dementia Care Program in Assisted Living Facilities</b>	<p>Individuals who are both COPES and Specialized Dementia Care Program-eligible with Alzheimer's disease or other dementia receiving care in a Specialized Dementia Care Program-contracted facility. Specialized Dementia Care Program eligibility is defined in <a href="#">WAC 388-106-0033</a>.</p> <p>In 2013, the Specialized Dementia Care Program served more than 880 clients. (See Appendix for more information.)</p>	<p>The Specialized Dementia Care Program offers services within Assisted Living Facilities that are dedicated solely to the care of persons with dementia. The program also provides care dedicated solely to persons with dementia in a separate unit 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 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 available statewide, based upon availability of qualified providers.</p>

<p><b>Community Options Program Entry Services</b></p> <p><b>Washington State's Medicaid Waiver-Funded Long-Term Supports and Services (LTSS)</b></p>	<p>To be eligible for Community Options Program Entry Services (COPES), clients must meet Nursing Facility Level of Care criteria. (See Appendix.)</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>Community Options Program Entry Services (COPES) provides personal care services to clients in-home, in a licensed Adult Family Home and in licensed Assisted Living Facilities. Additional services include: personal emergency response systems, home-delivered meals, specialized medical equipment, home modifications, nurse delegation, adult day care, caregiver/recipient training, adult day health, skilled nursing, transportation, adult dental services, community transition services, and home health aides.</p> <p>Services are not dementia-specific, but Adult Family Home providers or Assisted Living Facilities providing care for one or more clients with dementia are required to meet the requirements of Dementia Specialty Training (mentioned above).</p>
<p><b>Enhanced Service Facility</b></p> <p>(Effective Fall 2014)</p>	<p>Enhanced Service Facilities 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 through a 1915(c) waiver.</p>	<p>Enhanced Service Facilities offer behavioral supports, personal care assistance, medical or rehabilitative treatment, dietary services, security, chemical dependency treatment, and supervision in a specialized residential facility.</p> <p>The first Enhanced Service Facility bed will open in the Fall of 2014. The budget assumes 42 beds will be filled by June 2015. Expansion would require additional funding.</p>
<p><b>Expanded Community Services</b></p>	<p>Expanded Community Services are designed for clients with <u>exceptional care needs</u> 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>



<b>Health Home Services</b>	<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 settings. (See Appendix for more information.)</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 services, and use of information technology to link services, if applicable.</p>
<b>Medicaid Personal Care</b>	<p>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 <a href="#">Chapter 388-106 WAC</a>.</p>	<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>Medicaid Personal Care services are available in the client's own home, an Adult Family Home, or an Adult Residential Center.</p>
<b>New Freedom Consumer Directed Services Program</b>	<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>
<b>Program of All-Inclusive Care for the Elderly (PACE)</b>	<p>Individuals must be age 55 or older, meet Nursing Facility Level of Care (NFLOC), and live in the PACE service area. PACE is currently offered only in King County.</p>	<p>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; medications; nursing services; clinic visits; meals and activities. The center includes quiet space, activities, and a "wandering walk" tailored specifically to clients with dementia.</p>
<b>Skilled Nursing Facility Care</b>	<p>Skilled Nursing Facilities are for individuals whose conditions are complex and/or medically unstable and require frequent medical or nursing intervention.</p>	<p>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.</p>



Looking at all Skilled Nursing Facility clients (paid for by Medicaid, Medicare and private sources) approximately 41% of the population in Washington State has a diagnosis of Alzheimer's disease or related dementia.

## Moving Towards a More Dementia-Capable System

In 2011, the federal Administration on Aging outlined the need for 'dementia-capable' aging networks and long-term support service systems. They define model dementia-capable systems to be those with the capacity to address the unique needs of individuals with dementia who are losing their ability to take care of themselves and their family members who take on more and more responsibility for the needs of their loved ones.<sup>6</sup>

Washington State currently serves a significant number of people with dementia and their family caregivers in our aging network, the long-term services and support system and health care systems. For example, in the Family Caregiver Support Program, about 55% of 'care receivers' have either a probable or confirmed diagnosis of Alzheimer's disease or other dementia. The Family Caregiver Support Program has added dementia-specific services such as Memory Care & Wellness Services (dementia day program) and evidence-based services such as STAR-C (dementia behavior consultation) and the Reducing Disability in Alzheimer's Disease exercise program as grant and state funding allows; but such programs are limited to specific geographic areas of the state. The Family Caregiver Support Program has also integrated an evidence-based assessment and care planning protocol known as Tailored Caregiver Assessment and Referral<sup>®</sup> (TCARE<sup>®</sup>). Currently the Family Caregiver Support Program reaches only 1% of the state's 850,000 informal caregivers, many of whom are helping a person with memory loss/dementia.

Improvements to the Family Caregiver Support Program and the single-entry point system (e.g., Aging & Disability Resource Centers/Information & Assistance) might include an assessment of dementia-capability and the integration of dementia-capable protocols such as: identifying people with memory loss and/or their caregivers, making referrals for dementia diagnosis and to dementia specialty organizations at the 'front door' of the system, identification and dissemination of early stage interventions/services, expansion of current and other innovative evidence-based practices, and a more robust service budget per person and/or family caregiver.

A substantial group of individuals with dementia are also served in Medicaid-funded Long-term Services and Supports in various settings. Based on information in our CARE and MDS databases, we estimate 11% of in-home, 37% of Adult Family Home and 27% of Assisted Living Facility clients, and around 41% of Nursing Home clients are reported to have Alzheimer's disease or dementia. The Aging and Long-Term Support Administration has been operating the cost-effective Specialized Dementia Care Program in Assisted Living Facilities statewide through COPES since 2003. We must continue to actively develop resources and provider capacity to address the changing needs of the populations we serve including those with Alzheimer's disease.

Aging and Long-Term Support Administration has staff across the state actively working with community partners to develop strategies and resources. Aging and Long-Term Support Administration's Resource Support and Development Unit conducts ongoing needs assessments to determine the statewide and regional capacity to support individuals who experience behaviors which disrupt continuity of care and stability of care plans. Needs identified include: ongoing training and consultation to build the competency of residential providers for serving people with advanced dementia; additional contracted behavior specialists with expertise in dementia related behaviors to provide support and consultation to providers and state staff regarding individuals' behavioral challenges; and more residential providers who have the capacity to effectively serve clients with dementia related behaviors. While contracts with behavior specialists exist in each region and the number of beds available to serve clients moving from institutions has expanded statewide, gaps still exist, particularly in rural areas of the state.

Progress has been made in developing and providing basic training in dementia care for community care providers, but as mentioned, providers are continually challenged by the behavioral symptoms and needs of this population. In 2013, the Washington State Legislature passed Substitute Senate Bill 5630 to improve and expand training around the special needs of clients residing in Adult Family Homes. A process is underway to facilitate statewide stakeholder collaboration and develop consensus around ways to improve training related to dementia. This work includes evaluating the quality of existing Dementia Specialty Training and identifying recommendations for learning objectives, instructor qualifications, effective instructional techniques and student competency measures. Based on work and experience to date, the Aging and Long-Term Support Administration envisions learning objectives related to dementia care at both the basic level and at a higher, more advanced level of competency that may be consistently applied across various community-based long-term care settings. Dementia trainings will likely incorporate specific competencies for managers and caregivers and could eventually be linked to the ability to be credentialed as a dementia specialty provider with the completion of an advanced training.

Additional improvements to the long-term services and supports system might include an assessment of dementia-capability and the development of requirements and best practice guidelines for quality dementia care, as well as specific outcome measures in various settings related to dementia-capability.

## National and State Alzheimer's Plans

In 2012, the first National Plan to Address Alzheimer's Disease was released. The plan, calling for a comprehensive, collaborative approach acknowledges the critical need to better coordinate towards effective prevention, treatment and management of Alzheimer's and related dementias. Upon its release, United States Department of Health and Human Services Secretary Sebelius said, "This is a national plan—not a federal one, because reducing the burden of Alzheimer's will require the active engagement of both the public and private sectors." An update on the goals and activities of the plan can be seen at <http://aspe.hhs.gov/daltcp/napa/NatlPlan2013.pdf>.

The national Alzheimer's Association has called upon states to "create the infrastructure and accountability necessary to confront the sweeping economic and social impact of this disease. By bringing together essential stakeholders – such as state agency officials, legislators, care providers, family caregivers, and people with Alzheimer's – the state planning process is able to identify critical

issues, explore solutions, and construct a roadmap to guide a state's development into a dementia-capable state. Every state must develop a State Alzheimer's Disease Plan, and in those states that already have a published plan, efforts must be undertaken to ensure that the plan's recommendations are fully implemented."<sup>7</sup>

Washington State is currently one of a handful of states without an existing or emerging State Alzheimer's Disease Plan. While we have established a robust, statewide system of home and community-based long-term services and supports, there is room for improvement by integrating best practices and dementia-capability throughout the statewide system. And, there are opportunities to impact disease incidence through efforts to promote cognitive/brain health, opportunities to detect and diagnose Alzheimer's disease earlier to optimize the use of medications to address specific symptoms and allow individuals and families time to learn and plan, and opportunities to develop enhanced supports so individuals and their family caregivers can access public and private supports to sustain a greater quality of life while living with Alzheimer's disease. These improvements, though, will not occur without a comprehensive, collaborative approach.

On March 27, 2014, Governor Jay Inslee signed Senate Bill 6124 which provides legislative authorization to develop an Alzheimer's disease plan for Washington State. The Aging and Long-Term Support Administration will be leading this effort in partnership with stakeholders, educational institutions like the University of Washington, and consumers and families living with Alzheimer's disease.

## 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: <http://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** - 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 , and 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.

Aging and Disability Resource Centers serve as integrated points of entry into the home and community-based service and support system and are designed to address the frustrations many consumers and their families experience when they need to obtain information and access to services and supports. Through integration and coordination of existing aging and disability service systems, Aging and Disability Resource Center programs raise visibility about the full range of options that are available, provide objective information, advice, counseling and assistance, empower people to make informed decisions about their long term and other supports, and help people more easily access public and private long term supports and services programs. Timely supports can also prevent or delay the need to access government-paid services. By linking consumers with services and supports that match their individualized priorities and preferences, Aging and Disability Resource Centers have the ability to assist individuals to remain at home or in their communities and thereby support individual self-empowerment and quality of life. Aging and Disability Resource Centers rely on strong partnerships with other social services organizations; healthcare providers; and aging and disability advocates to create integrated networks. Thus far, 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.

**Area Agencies on Aging** are 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.

**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. Washington State's *Aging & Disability Resource Center*, now called *Community Living Connections*, has primarily concentrated its efforts on patient-centered, hospital-to-home care transitions using an evidence-based coaching model, Care Transition Intervention,<sup>®</sup> developed by Dr. Eric Coleman and his team at the University of Colorado at Denver. This model translates well with both patients and their informal support systems as well as to other care transition modalities. During a four week intervention, patients with complex care needs receive specific tools, are supported by a Transitions Coach,<sup>®</sup> and learn self-management skills to ensure their needs are met during the transition from hospital to home. Patients who participate in this program are significantly less likely to be readmitted and more likely to achieve self-identified personal goals around symptom management and functional recovery. Findings are sustained for as long as six months after the 30-day intervention.

The Aging and Long-Term Support Administration subcontracts with Qualis Health, the Medicare Quality Improvement Organization to provide ongoing technical assistance, mentoring, and shadowing to each of the Area Agency on Aging entities providing care transitions in Washington State. Qualis Health also works with the Washington State Hospital Association, a Centers for Medicare and Medicaid Services-designated Hospital Engagement Network to provide additional support to Hospital and Area Agency on Aging partnership development around care transitions.

Different geographical areas have garnered different funding sources that target specific populations and may not support serving others. Some of these funding sources are not directly under the purview of the Aging and Long-Term Support Administration, but may come directly from the Centers for Medicare and Medicaid Services, through the HealthPath Washington's Health Home and fully capitated strategies, or local funders. Additional funding used by Area Agency on Aging has come from Medicaid Home and Community Based Service Waivers, Older Americans Act Title IIIB and IIID funding and from a 3-year federal Aging and Disability Resource Center Enhanced Options Counseling grant.

Only the four pilot Aging and Disability Resource Centers (Northwest WA, Pierce County, Southeast WA, and Eastern WA) receive funding under the Affordable Care Act Section 3026, *Community Care*

*Transitions Partnership* demonstration. Several of the Area Agencies on Aging receive Affordable Care Act Health Home funding to serve the target high cost/high care dually eligible beneficiaries. Those that are using TIIIB or TIIID funding can serve persons 60+, regardless of the health insurance payer, but their capacity may be limited. All those using Aging and Disability Resource Center Enhanced Options Counseling grant funds or local funds can serve persons of all ages, but their capacity may be limited in some areas because written agreements with hospitals to share protected health information and to clarify referral processes may still be pending.

**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](http://www.TCARE.uwm.edu).

The Family Caregiver Support Program is funded through federal (\$2,807,974) and state (\$11,424,000) funds (2013).

**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: [http://www.hca.wa.gov/Pages/health\\_homes.aspx](http://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.<sup>8</sup>

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.<sup>9,10</sup>

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.<sup>11,12</sup> 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, ALISA 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.

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